

**Factors that influence patient empowerment in inpatient chronic
care: Early implementation experience with a diabetes care
intervention in South Africa**



Nina Abrahams

Student Number: ABRNIN002

Submitted in partial fulfilment for the degree

**MASTER OF PUBLIC HEALTH
(Health Systems Specialisation)**

At
THE UNIVERSITY OF CAPE TOWN

JULY 2018

Supervised By:

**PROF LUCY GILSON
PROF NAOMI LEVITT**

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

Plagiarism Declaration

I, Nina Abrahams, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:

Signed by candidate

Date: 02 July 2018

Abstract

The burden of non-communicable diseases is growing rapidly globally and especially in low- and middle-income countries. However, health systems around the world are not appropriately prepared for this increase in need for chronic care. Research suggests that health models that emphasise self-management and empowering patients to care actively for their disease are integral in non-communicable disease treatment as patients live with their disease well beyond contact with health services. Adherence and health-seeking behaviour literature suggest multiple factors within the lives of patients and within health systems that enhance or constrain patient empowerment interventions. However, in depth understanding of these factors are lacking in the South African context and especially in the inpatient setting as most research focuses on the role of primary care. This research used interviews with stakeholders in an upcoming inpatient diabetes intervention as a lens to qualitatively explore empowerment factors in further detail within the South African inpatient context. The study highlights multiple barriers to patient empowerment, namely the low socio-economic contexts of many South Africans who then struggle to access appropriate healthcare information and services and often have financial and emotional priorities that take precedence over their chronic illness. In addition, health services are bound by a shortage of resources and staff and ineffective communication systems which affects health professionals' ability to implement patient empowerment strategies. It also highlights the unique barriers found in inpatient care as the hospital emphasises short-term acute treatment – losing potential engagement time with patients. The study suggests that patient and provider contexts make encouraging patient engagement in long term chronic care difficult. However, knowledge of these factors can be harnessed to improve chronic care interventions in low- and middle-income countries.

Acknowledgements

I would like to sincerely thank my parents and brother, family, and friends for being supportive and patient through this process. I would also like to thank my supervisors, Prof Lucy Gilson and Prof Naomi Levitt, for their constant encouragement and for making me a better writer and researcher – I am forever grateful.

A huge thank you must also go to the hospital staff and patients who were gracious and helpful and made this research possible.

Acronyms

CCM	Chronic Care Model
CHEPSAA	Consortium for Health Policy and Systems Analysis in Africa
HICs	High-income countries
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
ICCC	Innovative Care for Chronic Conditions
IDF	International Diabetes Federation
LMICs	Low- and middle-income countries
NCDs	Non-communicable diseases
SES	Socio-economic status
TB	Tuberculosis
WHO	World Health Organisation

Table of Contents

Plagiarism Declaration	i
Abstract	ii
Acknowledgements	iii
Acronyms	iv
PART A: PROTOCOL	1
Background.....	1
Non-communicable diseases in South Africa	1
Chronic care models	1
The need for research on empowerment in chronic care.....	3
Focus on diabetes.....	4
Objectives	6
Research question	6
Aim.....	6
Justification.....	6
Study methodology	8
Conceptual paradigm	8
Conceptual framework.....	9
Study design	10
Phase one	11
Phase two	12
Sampling	12
Phase one	13
Phase two	13
Data collection.....	14
Phase one	15
Phase two	15
Data analysis.....	16
Phase one	17
Phase two	17
Ethical considerations.....	17
Study limitations.....	19

Timeframe	20
Budget	21
Dissemination of report.....	21
References	22
PART B: LITERATURE REVIEW	1
Introduction.....	1
Summary: review objectives	2
Literature search strategy	2
Chronic disease models.....	4
Current global health care model.....	4
Chronic care models	5
Self-management and empowerment	7
The hospital as a site for focus	9
Patient factors influencing their empowerment.....	9
Adherence and health-seeking behaviour	9
Focus on the LMIC setting	12
Patient influences over the health professional	13
The health system impact on patient empowerment.....	14
System Hardware influences over patient empowerment	15
Tangible and Intangible Software influences over patient empowerment	16
Summary.....	18
Justification for further research.....	19
References.....	20
PART C: JOURNAL MANUSCRIPT	1
Abstract	1
Background.....	2
Methods	4
Setting, sampling and data collection	4
Data analysis.....	5
Results	5
Socio-economic status and the ability of patients to engage in their own care	6
Health providers and the inpatient setting	13
Patient-provider relationship	18
Health providers and the health system setting	21

Discussion	28
Patient empowerment levels moderated by patient factors.....	29
Patient empowerment levels moderated by health system, provider, and inpatient factors.....	30
The implications of study findings	32
Limitations	33
Conclusion	34
References	35
APPENDICES	1
Appendix A: Invitation to participate in the research	1
Appendix B: Interview schedule for first phase	4
Appendix C: Informed consent	7
Appendix D: Ethics Clearance	10
Appendix E: Journal Style Guide.....	11

PART A: PROTOCOL

Background

Non-communicable diseases in South Africa

South Africa is currently facing a quadruple burden of disease between infectious diseases, non-communicable diseases, maternal and child mortality, and high rates of injuries [1,2]. Much focus in the past has been given to infectious diseases such as TB and HIV; however, in recent years the burden of non-communicable diseases (NCDs) – cardiovascular disease, diabetes, strokes, respiratory disease, and cancer – has grown to an estimated 30% of deaths in South Africa and is continuing to rise. The World Health Organisation (WHO) estimates that South Africa's NCD burden is two to three times that of developed countries and on par with countries with the highest rates in the world [1]. Specifically, rural and poor urban people are disproportionately affected [1].

NCDs share many of the same risk factors with each other such as ageing, smoking, a lack of physical exercise, unhealthy diets, and obesity [1]. Apart from ageing, these risk factors are preventable and could lead to a significant reduction in disease burden if accounted for. However, currently in South Africa's climate of increasing urbanisation, sedentary lifestyle, and cheap processed foods, NCDs are pervasive, chronic, and result in high levels of morbidity and loss of quality of life [3-5]. In addition, NCDs pose a huge burden on the health care system with South Africa spending nearly two billion American dollars on NCDs over the past ten years [6].

Chronic care models

NCDs often do not have a cure but rather require long term management that needs to be incorporated into everyday life [7]. Therefore, caring for people with NCDs extends beyond just the clinic or hospital setting. Currently, chronic care interventions that are implemented in low- and

middle-income countries (LMICs) often tend to be disease specific, fragmented, and not patient-centred which means that an individual's environment and multiple needs are not considered and this may lead to an inappropriate care plan [8]. This is of particular concern in South Africa where people face multiple barriers to accessing health care including slow, insufficient service delivery and unsatisfactory health provider interactions leading to many families becoming frustrated, 'giving up', and not continuing to engage with the health system at all [9]. These people may instead pursue alternative health management plans such as traditional and alternative medicine which could possibly have long term negative effects [10]. In addition, in South Africa, long term consultations and hospital care can result in catastrophic expenditure for households [9]. This can decrease the ability of a person to access appropriate care which leads to decreased health outcomes. Action needs to be taken to ensure that people are able to effectively manage their chronic care outside of the formal health care setting in order to not contribute more to the burden of NCDs.

Successful chronic care models around the world are often based on four components – supporting self-management of disease care, reshaping the delivery of health care to be adaptive and person-centred, increased support in decision making from experts, and integrated and effective communications systems in the referral pathway [11]. Chronic care models aim to develop an active and informed patient who interacts with health care professionals to shape the appropriate care plan that can be useful beyond the hospital setting. This is a change from acute disease care where the health professional is often regarded as the expert and solely in charge of patient management. In chronic care the patient and health professionals share authority and knowledge to develop long term, suitable programs [7]. After leaving inpatient care if a person is able to manage the chronic disease at home and integrate care into their normal everyday lifestyle then it serves as an inexpensive alternative to long term hospital disease management [12].

The need for research on empowerment in chronic care

While there is no set definition of empowerment, research tends to converge around measures of having control, being able to make decisions, believing in oneself, and being able to self-manage the disease [13]. For example, diabetes patients in empowerment-focused programs would receive counselling and training on making informed decisions around diabetes care as opposed to only learning to administer insulin. An empowered patient would therefore be more able to adapt, question, challenge, and change their daily practices in an attempt to maximise their physical, emotional, and social wellbeing [14]. In order to be adaptive and holistic, empowerment programs incorporate the social environment that an individual experiences outside of the formal healthcare setting to inform care practice [15]. When using a patient-centred approach and fully acknowledging patients' experiences, expertise, and priorities, health professionals can be active in promoting and facilitating patient empowerment as an outcome of care [16].

There is evidence to suggest that increasing patient empowerment as a noted outcome in health care has benefits for the person, community, and health care system. For example, in the United States, chronic programmes for patients with asthma and arthritis have shown that actively teaching self-management skills improved patient's clinical outcome compared to only giving patients disease information [17]. These programs also showed potential to reduce costs on the health system. In Sub-Saharan Africa, patient education has also been seen to be one of the least expensive diabetes interventions that can be implemented while still being highly effective [18]. A study in South Africa showed that not only did more patient-centred care for a range of chronic diseases enable the development of suitable and effective treatment plans but the increased knowledge and self-efficacy helped recipients justify financial and support needs to their family, friends, and community in order to access additional hospital care if needed [9]. These patients then served as a resource to further assist others in the community who are going through a similar

experience. Increased health outcomes, reduced cost on the health system, and becoming a community resource show the benefits of empowerment development that extends well beyond just the individual.

Initial research has shown positive effects of empowerment focused health care although more research needs to be done to understand what specific factors foster or inhibit the development of patient empowerment [14]. Developing countries like South Africa will need to take careful note considering the context of illiteracy, poor education, and extreme inequality that may hinder the development of an empowered patient [19]. In addition, Davy et al. found in their systematic review that not only does the patient context affect patient empowerment levels but the health system context also plays an important role [20]. This includes tangible factors such as access to resources and services as well as more intangible factors like the human relationship and communication style between patient and provider and the health system that help to facilitate greater health outcomes.

Prioritising empowerment based care falls in line with South Africa's aim towards developing a more patient-centred health system [9]. In line with this, the Western Cape government has introduced a new health care strategic plan for 2030 that highlights a person-centred approach to all levels of healthcare [21].

Focus on diabetes

Diabetes is a NCD characterised by abnormal sugar levels in the blood stream [22]. If sugar levels are not controlled then it can lead to various health complications such as kidney failure, heart attacks, strokes, and amputations. People can have Type 1, Type 2, or Gestational diabetes and often need to make permanent lifestyle changes by taking medication or injections and changing their eating habits and physical activity levels to help manage their disease.

The International Diabetes Federation (IDF) estimates that diabetes numbers in Africa will double by 2030 and NCDs will account for five times as many deaths as infectious diseases [23,6]. Burden of disease estimates have identified diabetes as a major and costly health problem in South Africa and many other countries. In the Western Cape, diabetes is the eighth most common cause of death and years of life lost among adults [24]. It is estimated that in South Africa in 2009 just under 79 000 years were lost due to disability attributed to diabetes [4]. In addition, if prevention strategies are put in place South Africa could reduce mortality by 20% as well as significantly delay premature death and disability – relieving the burden on the health system and on households [6]. The burden of diabetes, its co-occurrence with multiple diseases, its need for complete lifestyle changes, and its many negative health outcomes means that it serves as a relevant and useful marker for NCDs in South Africa.

In this research we will focus specifically on diabetes care, as one key service with relevance to NCD care more broadly. Participants will be sampled from those experienced with diabetes care at a major South African academic hospital. This hospital would like to introduce a new intervention to promote patient empowerment and improve long term diabetes care. The programme will consist of a number of components. For example a multidisciplinary team will be set up consisting of medical staff, administration, nursing, case management, pharmacy, nutrition, laboratory, quality improvement, pharmacology, and information systems. The team will review and revise current diabetes inpatient care with regards to administering and recording diabetes treatment. In addition the team will be trained to increase patient participation in their hospital care and so develop self-management skills of diabetes and facilitate empowerment of inpatients. Interventions like this would benefit from an exploration of the perceptions of patients and health professionals in order to be more appropriate and have a better chance of improving patient empowerment.

Objectives

Research question

- What factors of inpatient diabetes care influence patient empowerment in a South African hospital?

Sub question

- What contexts broadly explain empowerment development in chronic care?

Aim

The aim of this study is to explore what factors influence inpatient empowerment in a chronic care intervention for people with diabetes in a South African teaching hospital. It then aims to explain how and why these factors play out for which kinds of people and in what contexts. The study will try to understand the role of relevant contexts that may affect empowerment in South Africa such as patient demographics, acceptability of the intervention, ideas about chronic care and diabetes, and inequality and poverty [19,20]. It will also explore possible underlying mechanisms or influences such as collaboration and information sharing that facilitates the relationship between a person's context and their feelings of empowerment [13,25]. The study will contribute to the improvement of appropriate chronic care models in South African hospitals as well as facilitate possible scale up of the chronic care intervention under review to other health care facilities.

Justification

Empowerment serves as an important outcome of focus in chronic care as its development has been shown to improve health outcomes, decrease catastrophic health payments for patients, and decrease costs on the health system [9,17]. The focus on empowerment also validates the person-centred aim that the South African health system is currently trying to move towards.

Empowerment programmes can be used to improve effectiveness of person-centred care by

acknowledging the role the individual plays outside of a health-care setting when creating chronic care interventions [15].

There is currently limited research on empowerment in chronic care that has been conducted in Africa. For example, a systematic review looking at factors influencing implementation of chronic care models only found one appropriate study conducted in Africa out of an original search of nearly 3500 studies, with the majority conducted in American and Europe [20]. Another study attempting to conceptualise the definition of empowerment did not include any African based research [19]. Therefore there is a dearth of information for what affects, improves, and impedes empowerment development in a South African context.

The value of empowerment development as well as the lack of appropriate South African context-specific research in this area indicates the need for this study. This need is amplified considering the rapid growth of the burden of NCDs in an urbanising country such as South Africa [4]. Therefore, evaluating and understanding underlying inhibiting and promoting factors to empowerment will serve to build knowledge for the development of effective chronic care interventions. As a researcher, I am not involved in the intervention creation or implementation process. However, the intervention team have allowed me to access the hospital, diabetes patients, and health professionals in order to conduct this study. This research will take place at the beginning stages of this new chronic care intervention plan and so will be directly able to evaluate, influence, and change chronic care systems in real time, increasing research efficacy.

Study methodology

Conceptual paradigm

This study will broadly use a critical realist paradigm to guide the study design. Critical realism falls between two ontologies – one arguing that there is always objective truth that can be measured and observed and another arguing that everything is interpreted through the human mind and so all reality is subjective [26]. In other words, critical realism holds the understanding that there can be realities or truths in this world but these truths are constructed depending on a person and the context through which they are experienced [26]. This knowledge paradigm is useful as it combines the elements of both positive and constructivist understandings of knowledge to form a more comprehensive way of understanding the social world [27]. The paradigm is able to engage with possible causal relationships while still incorporating the complexity of humans and so can provide useful and practical solutions to social issues. Therefore, the critical realist paradigm will be used to help guide how questions are formed and analysed in this research.

Realist evaluation is founded in the critical realist paradigm. It assumes that while one can never get a definitive ‘objective’ measure on one true reality a researcher is still able to get close to a good understanding of how or why a program does or does not work using participants’ construction of events [26]. A realist evaluation also acknowledges that observable cause-effect relationships are in fact interacting with ‘deeper’ unobservable mechanisms that affect whether the context leads to a particular outcome. For example, a person can let go of a ball and the ball will drop, cause-effect, but it is in fact gravity, an unobservable mechanism, which facilitates this relationship [26]. In realist evaluation the researcher aims to create a programme theory on what contexts are important in predicting whether certain underlying mechanisms will or will not

operate and lead to particular outcomes [26]. This programme theory can then be used to improve the development and implementation of later similar interventions.

Conceptual framework

Realist evaluation is particularly appropriate “for evaluating new initiatives, pilot programmes and trials, or programmes that seem to work but ‘for whom and how’ is not yet understood...For evaluating programmes that will be scaled out, to understand how to adapt the intervention to new contexts” [26 p. 7]. While at the time of this research there will be no available evidence that this particular programme will increase patient empowerment and health outcomes, the programme is based on successful programme theory in other chronic care settings that strongly suggest it will have some effect. Therefore an evaluation approach influenced by realist evaluation will help to flesh out what aspects of the intervention affect possible changes in empowerment levels of inpatients.

In order to create feasible boundaries to research and to generate theory about intervention effects, a programme theory must first be developed [26]. This means that before the programme or intervention takes place, the researcher already has developed ideas about what contexts, mechanisms and outcomes could be at play. The theory will then guide the research and the questions later explored. The programme theory helps to give a starting point and realistic boundary to the research, helps shape questions used in data collection, and helps guide data analysis.

Firstly, in this study the programme theory has empowerment as the outcome of focus. Therefore the objective of the study is to look at how patients do or do not gain feelings of self-efficacy, self-awareness, ability of choice, self-determination, and ability to self-manage their disease [15,16]. Tangibly speaking, evidence of this outcome may manifest in many different ways

depending on what priorities and values the particular patient holds. Secondly, there are many different underlying mechanisms that could facilitate this feeling of empowerment. The literature suggests that if patients have information, are able to make sense of the chronic disease, why it has happened, and what support is available then this can lead to feelings of empowerment [13]. In addition, being a part of the decision making processes about managing their diabetes and collaborating with health professionals during their hospital stay can help increase empowerment [25]. Similarly, empowerment is facilitated by enhancing emotional coping and adjustment strategies as well as increasing a sense of hope for the future. Lastly, context makes a difference whether these mechanisms are able to come into play. For example, patient demographics, how acceptable the chronic care programme is to patients and health care providers, whether providers have knowledge, training, and are goal driven, the psychosocial health and financial status of patients, as well as resources such as time, funding, and collaboration available to the programme [20]. Certain contexts that are particularly prevalent in South Africa such as high levels of poor education, illiteracy, and inequality may additionally affect whether patients are able to become empowered to self-manage their diabetes [19]. This initial look at the literature will help guide the expectations of the researcher and direction of the research.

Study design

Evaluation work, by design, is an iterative and flexible process [26]. Flexible research means that the study design is not tightly pre-specified but rather the research design develops and adapts simultaneously as the research takes place [28]. For example, the interview schedule may change if initial interviews glean new and meaningful information that should be included for further exploration or new types of participants will be included if their absence is noted during data

review. Therefore sampling, data collection, and data analysis happen concurrently in order for the overall research design to unfold and evolve. This flexibility is appropriate for evaluation research as participants build and explain their experiences of a programme theory that is being tested and so the study needs to be receptive to any possibilities that participants may share.

This study will be conducted at the micro level of the health system. The micro level includes analysis of individuals and the relationships between them [29]. In this case individuals include patients, health care providers, and the intervention designers who will make up the sample of the study. This level of analysis is appropriate to this research as individual context and experiences will be integral to understanding and evaluating how chronic care and empowerment play out in different peoples' lives. It is especially fitting as this intervention aims specifically towards being people-centred. Knowing micro-level information, research at a meso and macro level of care can then begin to be developed and implemented in future.

The purpose of this research will be both exploratory and explanatory. Subsequently, this research will be conducted in two phases [30]. The first exploring and building theory on factors affecting empowerment and the second explaining and evaluating how these factors interact in the intervention to increase or decrease feelings of empowerment in diabetes inpatients.¹

Phase one

Firstly, exploratory research aims to create understanding, generate theory and ideas, and find out what is happening in little understood situations [29]. Therefore the first phase of the research will be exploring literature and participants' theories on empowerment and building hypotheses on its interactions with chronic care interventions as little is known about these factors in a South African

¹ The research actually conducted was limited to phase one of the work proposed due to delays in implementing the intervention that was to be evaluated. The range of respondents originally proposed across both phases of work was, however, maintained in the work conducted and the research questions were answered.

context. This phase will be conducted before the intervention is implemented in order to build a picture of current practices of patient empowerment in a South African hospital.

Phase two

The second phase of the study will adopt an explanatory purpose in order to explain patterns and relationships between phenomena that have previously been explored in literature and in with participants in the first phase of the research [29]. This phase will take place after the intervention is implemented in order to explain how the intervention affects these contexts, mechanisms, and outcome that were previously generated in the first phase.

Sampling

Purposive sampling is a non-random sampling technique whereby the researcher actively chooses participants based on their appropriateness to the study aims [31]. Deciding boundaries of participants' identity helps to ensure suitability to the research question and increases quality of the data received as the researcher is able to actively select a varied sample representing different contexts that may influence empowerment development [31,32]. In this study there will be three sets of participants – academic staff who are tasked with creating the intervention under review, health professionals, and inpatients who have diabetes.

Purposive sampling and a flexible study design means that no set number of participants is exclusively prescribed but rather participants are to be sampled based on what information is needed and how many participants are available – information that will become more apparent as the research progresses [31]. It is proposed that a minimum of five participants are needed per sampling group – namely, academic staff, health professionals, and inpatients – in order for data to be reliable, and so this number will be used as a guide [31]. This will result in approximately fifteen

to twenty interviews in total – between five and ten interviews in phase one and between ten to fifteen interviews in phase two. Bias is introduced in this sampling method as the researcher has control over who contributes towards data quality based on convenience or advice from experts in the diabetes care field [31]. This bias helps select participants who are relevant to the research and are willing to participate which contributes to greater depth of findings. As variability in the sample is ideal there will be limited exclusion criteria – participants need to be over the age of eighteen, have English as a first or second language, and be part of the intervention under review as a developer, implementer or patient.

For both phases invitation letters (see Appendix A) will be printed and the researcher will hand them over to potential participants using the network and knowledge of the intervention design team. Participants can then contact the researcher through email, call, messaging or via a health professional if they are interested in participating or want to ask further questions.

Phase one

Phase one will focus on sampling health professionals who are part of developing the intervention. These professionals will serve as key informants who can provide possible contexts and mechanism in regards to how the intervention could affect patient empowerment. Sampling these professionals in the first phase will help explore and build a programme theory on patient empowerment in an inpatient South African context. Health professionals who make up the multidisciplinary team as well as current diabetes inpatients can also be consulted during this phase in order to add to the theory.

Phase two

Phase two will focus more on sampling health professionals and patients in order to explore and test the theories on chronic care and empowerment interventions. Firstly, people with known

diabetes who are in inpatient care at the hospital at the time of the study will be able to share their experiences of the diabetes intervention and how it may facilitate their ability to self-manage the disease. Secondly, participants will be health professionals who are involved in caring for inpatients with diabetes and are trained in the intervention. They will be able to report on their and patient acceptability of the intervention and whether or not it was implemented as planned and what factors affected implementation. Depending on availability, participants in the second phase can include some of the same participants from phase one as this will increase robustness of the data. If not available, new participants will be sampled which will increase data information.

Data collection

This research will make use of one hour, face-to-face, audio-recorded, individual semi-structured interviews in order to build and evaluate the programme theory. Semi-structured interviews will be used as evaluation research, unlike many other qualitative methods, does not aim to gain general participant narratives about their experiences but rather is interested in specific events and processes that are hypothesised to be present in the programme under review [32]. Interview questions, while open-ended and flexible, will attempt to elicit core features of the programme theory that participants will develop and evaluate. Participants are considered the experts in their knowledge and experience and so the interviews serve as ‘assisted sense making’ to understand how those experiences build and then later align to the programme theory [32]. The interview schedule will be influenced by possible contexts, mechanisms, and outcomes that the participants can think through. For example, if staff characteristics are hypothesised to be a potential context that influences the programme in earlier interviews, then an exploratory question for subsequent interviews could be “What staff characteristics influence your feelings of being able or not able to regularly take your own medication?” Considering that the research is flexible, the interview

schedules may change in order to adapt to new information or new types of participants. All interviews will be conducted at the hospital at a time that is suitable for the participant. They will be primarily conducted in English; however, an interpreter will facilitate if required. The interpreter will be a staff member of the Division of Endocrinology and Diabetic Medicine at the University of Cape Town who is not directly involved in the intervention. They will be expected to have a background in qualitative research as well as be fluent in English and Afrikaans and/or Xhosa and/or another language that is spoken by the potential participant. The interpreter will be trained in the aims of the research as well as around definitions and understanding of empowerment before the interviews take place.

Phase one

The first phase will take place before the intervention is implemented in order to explore and build a suitable programme theory on chronic care and empowerment development [26]. Intervention experts, health professionals who work in diabetes care, and patients with diabetes will be able to share their views on the probable contexts and mechanisms that facilitate empowerment (see Appendix B). Questions will focus on participants' backgrounds, how they understand empowerment, and how they consider different aspects of hospital care as affecting empowerment. Early interviews will be considered as pilot interviews in order to ensure the suitability of the interview schedule. This first phase is particularly useful as literature on empowerment in chronic care in South Africa is lacking.

Phase two

The second phase will consist of semi-structured interviews with health professionals and diabetes patients in the hospital after the intervention takes place. These participants can then validate, explain, and evaluate the programme theory and how the intervention affected it. The interview

schedule of the second phase will be developed using literature on empowerment as well as information from the first phase of interviews.

Data analysis

Data analysis will be done simultaneously as interviews take place. In order to contribute to the rigour of the findings, the data will be triangulated across different interviews and between interview data and empowerment literature [30]. In other words, information will be compared across participants and against the literature in order to build and then later evaluate a programme theory. Following the critical realist paradigm, the researcher's interpretation of the data will be continuously validated with the participant or with other participants so that broad theory and understanding can be developed while still respecting that individuals are the experts on their own unique experiences [29,30].

Analysis of the interview transcripts will broadly follow a realist evaluation approach. This approach involves the researcher analysing and finding topics in the participant's transcript that may be considered as a context, a mechanism, or an outcome of importance [30]. The data is used to try and answer the question 'in this context, this mechanism performed for these kinds of people' which led to an increase or decrease in feelings of empowerment [26, p. 10]. The researcher may separate transcripts into different participant identities and contexts in order to analyse whether empowerment played out differently in these different types of participants [26]. Examples of participant contexts can include those who live in urban versus rural settings, gender of the participant, socio-economic status of the participant, or multiple diagnoses of the participant.

Phase one

The first phase of research aims to build a programme theory on empowerment and chronic care. Therefore, the whole narrative of interviews will be considered and coding of possibly important contexts, mechanisms, and outcomes identified from the literature and that can be seen in the interviews will be undertaken, and possible themes will be generated [30]. Initial exploration into empowerment status will follow common definitions in the literature. Namely, patient perceived control, skills development, confidence in using knowledge to make decisions about their care, believing in their skills, having hope for the future, and being able to self-manage their care [13,25,33]. More factors related to empowerment might also be identified from the interviews and explored.

Phase two

In the second phase of the study, portions of interview text will be coded in relation to the themes in the now established programme theory [30]. In critical realist research, the researcher makes judgements about how interview data fit with the predetermined codes, sometimes requiring interpretation of the interview [30]. For example, if the programme theory purports that empowerment is related to confidence in knowledge about administering medication then any text that implies this confidence will be coded as such. Participants can be consulted in order to validate the coding and findings and increase rigour of the study [29]. After this coding then comparisons and interpretation of findings can take place.

Ethical considerations

Ethics is an important consideration in research as it aims to minimise harm done to participants. Therefore, research ethical guidelines will be followed [34]. One way of ensuring patient integrity

and comfort is obtaining informed consent before each interview takes place [29]. An informed consent form (see Appendix C) gives participants all the information about the study such as research aims, data collection methods, how data will be used, how participant confidentiality will be ensured, and ways that participants may seek debriefing and follow up if they require. This process helps participants make an informed decision about whether or not to participate in the study. The informed consent form will be attached to the letter of invitation for the participant to initially look through. If the participant agrees to take part in the study then before the interview takes place the participant, researcher, and translator if needed will go through the consent form to clear up any questions, to establish understanding, and to sign two copies of the form – one for the participant and one for the researcher. The informed consent form will not be translated into other languages as participants will be expected to have some familiarity with English and the interpreter will help with any further translation.

While there may be no direct benefit to participating in the research, beyond contributing to improvement of chronic care in South Africa, there is also little risk as long as privacy and confidentiality is ensured. In order to ensure privacy and confidentiality of information health professionals may not be present during patient interviews, transcriptions of interviews and data write-up will use pseudonyms in order to protect participants' identities, and all information will be stored in a secure location that only the researcher has access to. Fortunately, since the researcher is not a part of the clinical care team there is little risk that participation in the research will affect the care received or job security. Therefore this study can be considered a minimal risk study.

Another ethical consideration is the role that the researcher plays in the research process. The researcher must be aware of possible power relations with participants in order to avoid participants feeling obligated or coerced into participating in the study [34]. This is especially pertinent as patients in a hospital could be considered a vulnerable group since they are reliant on

the care they receive. An essential part of the informed consent process before the interview takes place is making it very clear to participants that they have the choice to participate and may withdraw at any time with no repercussions to their medical care. The researcher must then continue to be aware of their role in the study proceedings with regards to power relations, bias, and preconceived ideas that may affect the way interviews are conducted and how data is analysed [35]. Being reflexive about the researcher's role in the study will therefore help protect participants as well as increase overall rigour of the study [29].

Ethical research also means conducting research that is significant and does not damage the health system in which it is conducted [29]. This ensures resources and time are not wasted and that the time the research takes does not inadvertently change relationships and processes in the health system leading to reduced health care impact. The flexible study design and professional relationship between researcher and intervention implementers will help ensure that the research findings are meaningful and implementable and that the hospital system is continuously considered and adapted for.

Study limitations

There are several limitations to this research work. Firstly, because of time and financial constraints, the research will only focus on one empowerment intervention and so will not be able to explore the effects of different intervention strategies. Secondly, as this research takes place in a tertiary hospital it may lose out on possibly relevant and currently unexplored contexts of primary and community chronic health care settings. The study will also be interviewing patients while they are in a hospital setting which may not reflect their feelings of empowerment once they are back in their home environment.

These limitations are important to report in data dissemination so that any use of the findings do not go beyond what the study can claim. However, considering the scope of the research, the lack of research in South Africa, and the important role empowerment can play in patient care; the study will still be able to produce meaningful and useful findings despite possible limitations. These findings can then be repeated and built upon in later research in order to create a fuller picture of chronic care in multiple contexts [31].

Timeframe

The interview process will begin as soon as ethical clearance is acquired. The aim is to start before the intervention under review is implemented or at the beginning of its implementation in order to conduct the first phase of interviewing in June and July 2017. The second phase of interviews will take place from August to October 2017 after the intervention has been established. As this research follows a flexible design, many of the components will be done simultaneously. The final write up will begin at the end of December 2017 and to be completed in February 2018.²

Activity	Dates
Protocol edits	February 2017 – May 2017
Protocol to ethics review	June 2017
First round of interviews	June 2017 – August 2017
Literature review	June 2017 – August 2017
Second round of interviews	August 2017 – October 2017
Data analysis	Throughout interview process
Formal data analysis	October 2017 – December 2017
Journal article write-up	December 2017 - January 2017
Intend to submit	February 2018

² This timeframe was delayed due to the intervention under review requiring more time to develop its protocol

Budget

This research will be self-funded and there are no conflicts of interest. Resources that will be acquired by the researcher are (estimated cost):

- Stationary (R100)
- Voice recorder (to be borrowed)
- Participant snacks (R500)
- Printing of information sheets, consent forms, interview schedule (R50)
- Printing of dissertation paperwork (R50)
- Transport (R200)
- Contingency (R100)

Total is R1000

Dissemination of report

The study findings will be presented as a research article created for possible publication in a journal that focuses on chronic health care and/or health systems. The findings will also be shared with participants including patients, health professionals, and chronic care programme developers as well as other relevant stakeholders such as the hospital administration. The research information will be freely available to all interested stakeholders

Post-script: note to examiner:

The research actually conducted was limited to phase one of the work proposed here, due to delays in implementing the intervention that was to be evaluated. The range of respondents originally proposed across both phases of work was, however, maintained in the work conducted, and the original research questions were answered.

References

1. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D. The burden of non-communicable diseases in South Africa. *The Lancet*. 2009; doi:10.1016/S0140-6736(09)61087-4.
2. Yerramilli P. South Africa's quadruple burden of disease. 2015. http://blogs.plos.org/globalhealth/2015/03/southafrica_quadrupleburden/. Accessed 23 Mar 2017.
3. Beaglehole R, Bonita R, Alleyne G, Horton R, Li L, Lincoln P, et al. UN high-level meeting on non-communicable diseases: Addressing four questions. *The Lancet*. 2011; doi:10.1016/S0140-6736(11)60879-9.
4. Bertram MY, Jaswal AVS, Van Wyk VP, Levitt NS, Hofman KJ. The non-fatal disease burden caused by type 2 diabetes in South Africa, 2009. *Global Health Action*. 2013; doi:10.3402/gha.v6i0.19244.
5. Ruder S. How South Africa can beat its sugar-fuelled diabetes epidemic. 2016. <https://theconversation.com/how-south-africa-can-beat-its-sugar-fuelled-diabetes-epidemic-68682>. Accessed 23 Mar 2017.
6. Hofman K. Non-communicable diseases in South Africa: A challenge to economic development. *South African Medical Journal*. 2014; doi:10.7196/SAMJ.8727.
7. Holman H, Lorig K. Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports*. 2004; doi:10.1016/j.phr.2004.04.002.
8. Samb B, Desai N, Nishtar S, Mendis S, Bekedam H, Wright A, et al. Prevention and management of chronic disease: A litmus test for health-systems strengthening in low-income and middle-income countries. *The Lancet*. 2010; doi:10.1016/S0140-6736(10)61353-0.
9. Goudge J, Gilson L, Russell S, Gumede T, Mills A. Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 2009; doi:10.1186/1472-6963-9-75.
10. Peltzer K. Utilization and practice of Traditional/Complementary/Alternative Medicine (TM/CAM) in South Africa. *African Journal of Traditional, Complementary, and Alternative Medicines*. 2009; 6(2):175-185.
11. Epping-Jordan J, Pruitt S, Bengoa R, Wagner E. Improving the quality of health care for chronic conditions. *Quality & Safety in Health Care*. 2004; doi:10.1136/qshc.2004.010744.
12. Lowes L, Lyne P, Gregory JW. Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*. 2004; doi:10.1111/j.1464-5491.2004.01193.x.
13. McAllister M, Dunn G, Payne K, Davies L, Todd C. Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Services Research*. 2012; doi:10.1186/1472-6963-12-157.
14. EMPATHiE Consortium. Empowering patients in the management of chronic diseases (final summary report). Health Programme of the European Union. 2014. http://ec.europa.eu/health/sites/health/files/patient_safety/docs/empathie_frep_en.pdf. Accessed 14 Apr 2017.
15. Pulvirenti M, McMillan J, Lawn S. Empowerment, patient centred care and self-management. *Health Expectations*. 2014; doi:10.1111/j.1369-7625.2011.00757.x.
16. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*. 2006; doi:10.1016/j.pec.2006.09.008.
17. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA*. 2002; doi:10.1001/jama.288.19.2469.
18. Gill GV, Mbanya JC, Ramaiya KL, Tesfaye S. A sub-Saharan African perspective of diabetes. *Diabetologia*. 2009; doi:10.1007/s00125-008-1167-9.
19. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M, et al. Conceptualising patient empowerment: A mixed methods study. *BMC Health Services Research*. 2015; doi:10.1186/s12913-015-0907-z.
20. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, Brown A. Factors influencing the implementation of chronic care models: A systematic literature review. *BMC Family Practice*. 2015; doi:10.1186/s12875-015-0319-5.
21. Western Cape Government Health. Healthcare 2030: The road to wellness. 2014. <https://www.westerncape.gov.za/assets/departments/health/healthcare2030.pdf>. Accessed 20 Apr 2017.

22. Ferry R. Diabetes Treatment. 2016. http://www.medicinenet.com/diabetes_treatment/article.htm. Accessed 20 Mar 2017.
23. Netcare Medical Scheme. Making a difference to the diabetes pandemic. <https://www.discovery.co.za/portal/individual/diabetes-pandemic>. Accessed 23 Mar 2017.
24. Groenewald P, Msemburi W, Morden E, Zinyakatira N, Neethling I, Daniels J, et al. Western Cape Mortality Profile 2011. Cape Town: South African Medical Research Council. 2014. <http://www.mrc.ac.za/bod/WC2011Report.pdf>. Accessed 20 Apr 2017.
25. Barr PJ, Scholl I, Bravo P, Faber MJ, Elwyn G, McAllister M. Assessment of patient empowerment: A systematic review of measures. PLoS ONE. 2015; doi:10.1371/journal.pone.0126553.
26. Westhorp G. Realist impact evaluation: An introduction. Methods Lab. 2014. <https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9138.pdf>. Accessed 15 Mar 2017.
27. Fletcher AJ. Applying critical realism in qualitative research: Methodology meets method. International Journal of Social Research Methodology. 2017; doi:10.1080/13645579.2016.1144401.
28. Robson C. Real World Research: A resource for social scientists and practitioner-researchers. 2nd ed. Oxford: Blackwell Publishing; 2002.
29. Gilson L. Doing health policy and systems research: Key steps in the process. In: Health policy and systems research: A methodology reader. World Health Organisation. 2012. http://www.who.int/alliance-hpsr/alliancehpsr_reader.pdf. Accessed 09 Nov 2016.
30. Sobh R, Perry C. Research design and data analysis in realism research. European Journal of Marketing. 2006; doi:10.1108/03090560610702777.
31. Tongco MDC. Purposive sampling as a tool for informant selection. Ethnobotany Research and Applications. 2007;5:147-158.
32. Manzano A. The craft of interviewing in realist evaluation. Evaluation. 2016; doi:10.1177/1356389016638615.
33. Small N, Bower P, Chew-Graham CA, Whalley D, Protheroe J. Patient empowerment in long term conditions: Development and preliminary testing of a new measure. BMC Health Services Research. 2013; doi:10.1186/1472-6963-13-263.
34. Orb A, Eisenhauer L, Wynaden D. Ethics in qualitative research. Journal of Nursing Scholarship. 2001;33(1):93-96.
35. Groenewald T. A phenomenological research design illustrated. International Journal of Qualitative Methods. 2004;3(1):1-26.

PART B: LITERATURE REVIEW

Introduction

The world is facing a rapidly increasing burden of non-communicable diseases (NCDs). In 2005 NCDs were responsible for 60% of world mortality and nearly half of these deaths occurred in people younger than seventy years of age. It is estimated that by 2020 NCDs will be responsible for 70% of global deaths and that the largest mortality and morbidity burden from NCDs will occur in low- to middle-income countries (LMICs) [1]. By 2030 NCDs will account for 5 times as many deaths as infectious diseases in LMICs and 80% of global death from NCDs will occur in these countries [2,3]. The World Health Organisation (WHO) estimates that in 2004 NCDs were the cause of nearly one third of the burden of disease in South Africa and that, compared to 23 other low- to middle-income countries, South Africa has the third highest death rate due to NCDs per 100 000 adults – with cardiovascular disease and diabetes contributing the largest load [4,5].

The under-resourced and acute-care focused context of the South African health system means that health professionals are often not able to provide the long term care that patients with chronic diseases require [6]. Internationally, however, evidence suggests that empowering patients to proactively engage in chronic care while they are in a health care setting may be an integral part of improving their health outcomes and wellbeing well beyond their care stay [7].

To better understand the potential and challenges of efforts to empower patients with chronic diseases, this narrative literature review will first explore different health care models and how they aim to improve the health outcomes of those with chronic diseases. It will then look at the justification for why health providers should facilitate patient empowerment, specifically considering inpatient chronic care programmes in low- to middle-income settings such as South Africa. Finally, it will consider what factors may affect efforts to empower patients to engage in long

term care. It will do this by firstly exploring what parts of the patient's own life may affect their engagement with the health system and then secondly how characteristics of the health system itself may affect the ability of health services to improve patient empowerment.

This review is undertaken to inform the small-scale qualitative evaluation of a new hospital inpatient intervention that aims to increase patient self-management of their diabetes, reported in part C of this dissertation. For this evaluation, it is important to understand the broader context around chronic disease programmes, as well as what contexts facilitate and affect patient empowerment levels.

Summary: review objectives

- To review the literature on chronic care models
- To explore the role of patient empowerment in chronic care
- To evaluate how patient context may affect patient empowerment
- To evaluate how health systems may affect patient empowerment

Literature search strategy

The following search terms were utilised in order to refine the search and review the relevant literature:

Patient empowerment; patient empowerment AND chronic; chronic care AND model; chronic care AND hospital; self-management AND patient; self-management AND empowerment; barriers AND health; barriers AND health care AND chronic; patient characteristics AND empowerment; adherence AND chronic; health seeking behaviour; health seeking AND chronic; health seeking AND income countries; health seeking AND Africa; doctor-patient communication; health system AND

empowerment; health AND framework AND software; health system AND relationships OR power; health system AND values OR norms; health system AND complex.

All these terms were searched independently as well as compounded with 'South Africa' in order to find both international and local research that could help inform the findings of the current research.

For search sources the following search databases were used via the University of Cape Town Libraries platform: PubMed and Google Scholar. These two databases were chosen as they serve as reputable information sources for peer-reviewed articles –the former health specific and the latter not limited to health care. Only choosing two databases helped to contain the scope available to this research project.

Inclusion criteria included relevant peer-reviewed English written or translated articles that focused on chronic disease care. The search focused particularly on including review papers. Further reviews and stand-alone empirical studies were found using hand searches of the references within the articles identified through the database searches. Only publications dated since 2000 were included in this review in order to keep the findings up to date with current practices, and because it was judged that earlier seminal papers would be likely to inform post-2000 articles.

The literature identified through these approaches was then categorised and considered further under three themes, reflecting the review objectives:

Chronic disease models

The literature identified through the search offers different definitions and types of chronic disease care models as well as indicates which models are being used currently and provides evidence on their effectiveness. Models that incorporate self-management and patient empowerment

Factors that influence patient empowerment in inpatient chronic care components are specifically explored in this review. While the available models are largely based on primary care, a further analysis of the hospital's role in chronic care is explored.

Patient factors influencing patient empowerment within chronic disease care

The empowerment literature identified through the search indicates that the background of the patient is one key influence over patient empowerment. Different contextual factors such as employment, living arrangement, and poverty levels may affect how much a patient is able to engage in their care within and beyond the health care setting. This review explores, then, what makes an empowered patient.

The health system impact on patient empowerment within chronic disease care

Another critical influence over patient empowerment is how it is supported or constrained by the health system context. The literature identified through the search considers factors about health services that can enable patient empowerment programmes, such as better use of resources, better motivation of staff, and more time for patient-centred care.

Chronic disease models

Current global health care model

Despite the increasing burden of NCDs which were responsible for over two thirds of global death in 2012 [8], health systems around the world still largely reflect an acute care model. Namely, health interventions are expected to be relatively short, the doctor is considered the professional and the patient the passive receiver of health care, and the outcome is expected to be that of recovery from the disease [9-12]. A comment piece, led by the director of the United Nations' University's International Institute for Global Health, based in Malaysia, has argued that in many

LMICs those that present with chronic diseases are still often only treated for the acute symptoms of their disease, resulting in repeated need for the health system and, as not tackling their causes, increased prevalence of NCDs [9,12]. A review of health systems in LMICs by the WHO and chronic care experts also found evidence of this acute focus [13]. This review highlighted the Caribbean as a prime example of the LMIC chronic care situation: half of the patients attending diabetes clinics had poor blood glucose control and over a year period only one third had received advice about diet, whilst only 5% had received advice about physical activity. In addition to patients not receiving adequate chronic care the cost burden to families and to countries is also rising as prevalence of NCDs increases. Allotey et al. highlighted Cameroon as an exemplar LMIC experience - where in 2002 the cost of diabetes care per patient in 2002 was 50 times that of the per-capita government budget [9]. As it is an LMIC with a high burden of chronic disease, these experiences suggest that South Africa needs to think again about its own health care model.

Chronic care models

A wide ranging systematic review of chronic care interventions, focusing not only randomised control trials and cohort studies but also qualitative work in the field, found both that the most widely used model for an NCD-focused health system in high income countries (HIC) is the Chronic Care Model (CCM) and that most chronic care interventions are at least loosely based on this framework [14]. This framework, developed for primary care, aims to encourage the development of an informed and active patient as well as proactive health workers that collaborate when creating treatment plans [13]. The components that make up the CCM are: self-management support, whereby patient and health professionals collaborate to make relevant and sustainable treatment goals; delivery system design, whereby the health system changes from an acute disease focus to prioritising the role of non-physicians and close follow up; decision support, whereby

health workers have access to specialists and evidence based information; and clinical information systems, whereby health professionals build an understanding not only of the disease but also the context of the patient and what types of people have the disease [13,15]. A further systematic review of treatment interventions in HICs that aligned with the CCM model found that chronic disease programmes that implement most aspects of the CCM result in improvements in quality of care, including a reduction of the risk of heart disease in patients with diabetes, and a decrease in hospital visits for those with congestive heart failure [10]. This CCM literature, thus, indicates that it is a promising framework for all health systems to use in order to manage the growing NCD burden.

However, it is recognised that in the context of insufficient resources and inadequate access to medication and technology, LMICs may struggle to implement the CCM model [13]. With this in mind, the WHO brought together health leaders from Africa, Asia, Latin America, and Eastern Europe to analyse and discuss the relevance of the CCM in their settings. From this dialogue, the Innovative Care for Chronic Conditions (ICCC) framework was established to serve as a road map specifically to help LMICs change their health system priorities while keeping in mind their unique needs. The ICCC conceptually aligns itself to the CCM; however, it expands the productive interaction component of the CCM from patients and health providers to include community partners. In addition, it argues that patients should not only be motivated but, in the context of low resources, should also be 'prepared' and have access to necessary equipment. The ICCC also strongly focuses on collaboration of care between different types of health services that are often fragmented in LMICs – this includes intimately linking policies and strategies between primary and hospital care [13].

Self-management and empowerment

While difficult to disentangle and isolate the elements of a CCM aligned health intervention, a literature review on the effectiveness of individual CCM components found that self-management may be a fundamental factor in achieving positive outcomes [15]. Of the 20 studies reviewed that included patient self-management training as part of the intervention, 19 showed improved patient health outcomes. Similarly, the review of chronic care interventions implemented globally found that the vast majority of CCM interventions resulted in improved health outcomes or health care processes, and that most of these interventions incorporated self-management elements [14]. These positive consequences could be because a patient lives with, and manages, their chronic disease long after any health care visit or possible intervention and over a long period of time. Therefore the greatest effects are seen when patients are able to take control of their lives and have the willingness and ability to continue to care for themselves over time, and so are not continuously reliant on the formal health system [13,15].

Self-management involves educating patients about their disease as well as training them in problem-solving skills and goal setting [15]. Within the framework of the CCM, self-management interventions include collaboration between patient and health professionals in developing relevant health care plans and goals that require both the medical expertise of the health care provider as well as the expertise of the patients on their main concerns, aims, abilities, values, and culture, both backed up by resources that allow patients to care successfully for their disease outside of the care setting [16]. For example, in diabetes care, self-management training may include increasing patient understanding of the disease and its care, developing individualised plans around changing lifestyle factors such as diet and exercise, developing skills to self-monitor blood glucose and prevent or identify possible complications such as foot and eye care, use of support groups, as well as improving coping skills and promoting empowerment, motivation, relaxation

skills, and self-efficacy [7,14]. One systematic review of randomised controlled trials looking at the effects of self-management training in diabetes care found improvements in patient knowledge, diet, healthcare skills, metabolic control, psychological outcomes such as problem solving and anxiety levels, and weight loss [7]. The investment into knowledge, skills, action plans, and tools can, then, be effective in improving patient clinical outcomes as well as reducing the NCD burden on the health system.

A recurring concept in the patient self-management literature is that of patient empowerment [7,17,18]. This term has been used in various ways and with multiple definitions. However, concept analyses conducted on the term found that in general an empowered patient is understood in the literature to be a patient that is motivated to understand their condition and has the self-confidence to actively make decisions about their care. Empowered patients also tend to feel that they have control over their disease care and are able to adapt to circumstances in order to manage it effectively [17-20]. Another concept analysis conducted by widely-cited authors in the patient empowerment field found that empowerment can be understood to be both a process, whereby a patient learns to think critically and act independently, as well as an outcome, whereby, through a health intervention, the patient achieves a sense of self-efficacy over their ability to manage the disease [16,18]. An empowerment focussed health intervention is, then, patient-centred, values co-creation of knowledge between health professional and patient, and strives to enhance patient knowledge and capacity to make decisions about their care [19]. Interventions may include motivational interviewing, patient-centred training, counselling and health coaching, and appropriate referrals to health services [18]. Facilitating empowerment can encourage a person to not only self-manage their disease over a long period but also to be engaged, adaptive, and motivated to make positive changes in all aspects of their life to better manage their health.

The hospital as a site for focus

Currently a large focus of CCM literature is on the role it plays in primary care as this is the level of care for which it was developed [14,15]. However, the CCM and ICCC are not discrete interventions with clear instructions but rather frameworks that can be adapted to local health system contexts [10]. Therefore, while originally targeting primary care, both models, particularly the ICCC, encourage patient empowerment and self-management thinking at all levels of care, including that of hospital care. For example, hospitalisation is a prolonged point of contact between health professionals and patients that could potentially be used for educating and training in knowledge and skills that the patient has forgotten or not previously gained [21,22]. In addition, as focus and resources move towards primary care, especially in LMICs, tertiary care needs to become more effective in order to continue to provide its services with less funding [23]. This includes helping patients care for their disease in a way that reduces adverse effects and prevents re-admissions. It is important to note however that inpatients are not the same as outpatients, as they are sicker, they may not be able to take on as much responsibility, they may be on multiple medications, and they may have different goals at this point of care [24]. Therefore there is value in researching the potential, but as yet unclear, role that CCM and ICCC components can play in the unique setting of the hospital.

Patient factors influencing their empowerment**Adherence and health-seeking behaviour**

The CCM model suggests that, compared to a disengaged person, an engaged and motivated person is more likely to seek out and use effective health services and make changes to their lifestyle for better health outcomes [25]. However, there are multiple and complex factors that can

influence how and why people engage with the health system and their motivation and empowerment to do so. A meta-analysis of adherence literature, for example, found that a patient's continued engagement with their health system, especially their continued follow up of a long term medicine regimen, can be moderated by four interacting clusters of factors [26]. First are socio-economic factors that have a negative effect on adherence, such as lack of family and social support, low family education, stigma of the disease, high cost of treatment, and low income. Second are disease related factors, such as being asymptomatic or feeling cured or having a psychiatric, comorbid or long term illness. Third are treatment related factors, such as having an unproductive patient-provider relationship, having a complex treatment plan that requires lifestyle changes, and having adverse effects from medication. Last are patient-related factors, such as being younger, male, single or divorced, having low education, unstable housing, a history of substance abuse, having a low sense of self-worth, and having opposing or negative attitudes or cultural beliefs towards the diagnosis or treatment. These factors all come into play when a patient is on their journey through the long and complex journey of chronic disease care and all affect how they may engage or not engage with a potential treatment plan.

Reviews of health-seeking behaviour literature in low- to high-income countries suggest similar factors influence broader patient decision-making. They include social factors such as age and sex, cultural factors such as gender expectations, socio-economic factors such as occupation and educational levels, economic factors such as cost of care, and geographical factors such as distance to health providers. People's care seeking behaviour can also be influenced by available information, past experience, motivation levels, severity of illness, poverty levels, acceptability of treatment plan, and availability of health services [27,28].

Specific studies from higher income settings offer further insights into these barriers and facilitators to NCD care access and use. A qualitative study in the United States explored the internal

and external barriers to engaging with the health system among a cohort of lower income African-Americans who were enrolled in a chronic disease self-management programme, and who had poor health outcomes [25]. Internal barriers included postponing seeking care because they were either in denial about their disease, embarrassed to talk about their disease, feared their disease status would become known to others, or they had no symptoms. Additionally many also had mental health issues including depression, schizophrenia, and isolation, largely due to their poverty status. External barriers to engaging in care included not having permanent housing which meant many only had short term goals that did not prioritise health or they could not store medication. Participants noted the importance of having education and peer support in overcoming these barriers as it provided a safe space to talk about and better understand their health needs. Another qualitative study conducted in an American academic tertiary hospital interviewed patients with diabetes that were readmitted within thirty days of discharge [29]. They found that patient characteristics such as poor health literacy, poor recall of medication and discharge plans, difficulty in getting transport to appointments, difficulty in preparing the correct foods and getting medication, and feelings of powerlessness over their disease contributed to poor health outcomes and readmission to hospital.

Interestingly, even in higher income societies, with excellent and accessible education, housing, transport, and health services, personal patient characteristics continue to play a role in broader healthcare engagement. For example, a representative survey of Finnish adults found that despite equal access to healthcare, there were large gender disparities in types of ill-health and that females still tend to live significantly longer than males [30]. In this study, women were more interested in health information, were more active in finding health information, were more interested in world health pandemics, were more aware of how their purchases affected their health, and were more receptive to health advice from those around them. It is therefore vitally

important to understand the characteristics and context of a patient as these characteristics can influence patient empowerment and engagement with health services. In turn, this knowledge can be used to encourage health seeking and to provide appropriate and effective chronic care.

Focus on the LMIC setting

Studies of general health seeking behaviour in LMICs suggest that gender, poverty, and education are vital influencing factors for health seeking behaviours. For example, studies conducted in Pakistan, Kenya, and Malawi found that increased poverty and rural status led to decreased health seeking in the formal health sector [31-33]. However, this was relevant even in places that offered free government health services implying that other factors, such as the cost of transport, lost income days or mistrust in the health system may play a role beyond health service affordability. A literature review of economic consequences of health-seeking in LMICs found that, in order to receive formal health services, many households spend a catastrophic amount of their income on unaffordable medicines, transport, nutritious foods, unofficial or 'under-the-table' payments to health professionals, and accommodations for those travelling with the sick person [34]. In addition, some studies in this review estimated that for chronic care indirect costs, such as taking time off work, could cost a household two to three times as much as direct healthcare costs. Households may then be forced to use unsustainable coping strategies such as borrowing money, selling assets, reducing food consumption, and putting children to work in order to receive care which may demotivate a person from seeking care. In addition, contradictory to the Finnish study cited earlier, where women are more likely to seek care, it was found that in many LMIC settings males are often the heads of households and so hold more economic and decision making power than women, allowing them to seek health care faster than females who were reliant on their male household members to access care. In these countries as well as Uganda and Tanzania people are

more likely to present to formal healthcare when education levels are higher as they may have more knowledge of diseases and their symptoms compared to those with lower education who tend to only present once the disease symptoms become severe [35,36].

The South African health seeking behaviour literature reflects findings from other LMICs in many ways. Large household surveys and interviews have found that rural and poor South Africans have the most difficulty accessing adequate healthcare compared to wealthier counterparts. Even though many health services are free often people still cannot afford the transport cost and, if employed and able to afford transport, are unable to take time off from work to travel the long distances to health providers [6, 37, 38], For the most vulnerable households, repeated clinic and hospital visits for consultations and to pick up medicines cost 30 – 50% of their monthly income, excluding the cost of following a prescribed diet and possible lifestyle changes that need to be implemented for chronic care [6]. South Africans also often mistrust public health services, expecting bad service or mistreatment from staff, and this puts them off seeking care - meaning many only seek formal health care once a disease becomes severe [37]. Unlike in many other LMICs, however, South African gender health care seeking patterns resemble HICs with women more aware of their chronic disease and more likely to be on treatment and be admitted to inpatient care than males [38,39].

Patient influences over the health professional

Patient characteristics not only influence patient actions but can also influence health provider actions, with consequences for patient motivation to continue care. A systematic review exploring patient socio-economic status and doctor-patient communication in HICs found, first, that patients who had a lower socio-economic background had a more passive communication style - such as asking less questions and giving less opinions of their treatment plan - compared to patients from a

higher socio-economic class, and second, health providers were more likely to focus on physical examination, tell lower income patients what to do and give them less treatment information rather than involving them in treatment decisions [40,41]. Similarly, a 2015 Canadian study focussed on emergency medicine practitioners found that, when faced with a patient's context, health providers were significantly less likely to follow known clinical guidelines and instead tailored treatment towards the patient's specific needs [42]. Patient characteristics included patient occupation, how close they were to care, what expectations the patient had, and home-life factors such as living alone versus with others. In South Africa, a country with eleven official languages and inadequate access to interpreters, health professionals and patients often become frustrated with each other and do not share vital health information due to language and cultural barriers [43].

The health system impact on patient empowerment

The characteristics of the health system itself may also influence the initiation and continuation of chronic care [27]. In thinking about health systems, it is useful to recognise that every system is a dynamic whole made up of hardware, as well as tangible and intangible software, as seen in Figure 1 [44-46]. A system's hardware refers to dimensions such as staff numbers and types, finances, infrastructure, medicinal and technological resources, and organisational structures. A system's software on the other hand contains tangible elements such as information use, skills development, decision making processes, and planning and budgeting processes. Intangible software, meanwhile, refers to the role of values, power, trust, and norms that govern actions between the people who work within the system, including patients. This framework can be used in thinking through the influence of the health system on patients' motivation to seek and continue care.

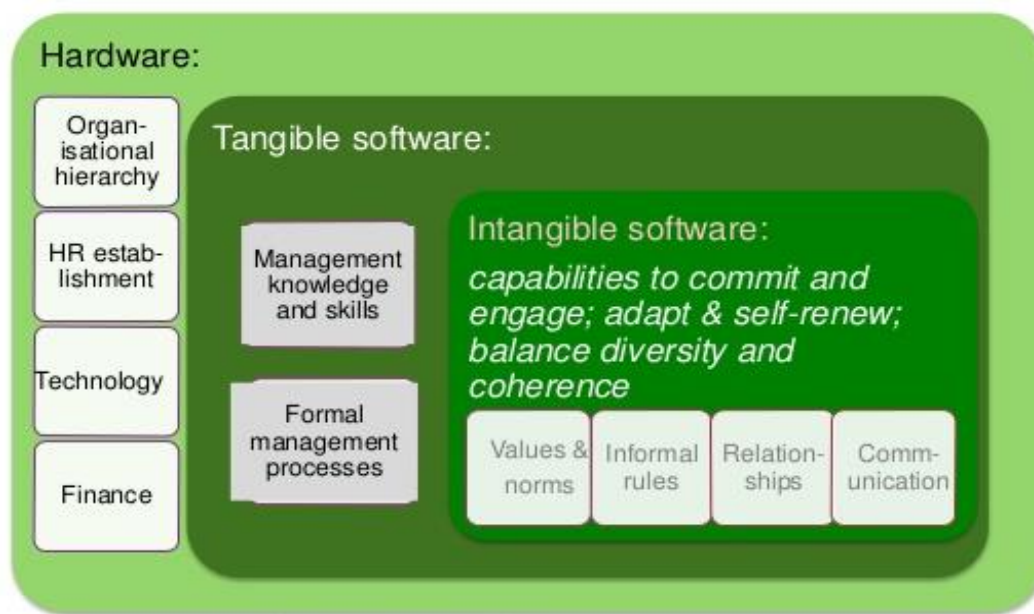


Figure 1 Health system: hardware and software model

System Hardware influences over patient empowerment

An extensive literature review on health system barriers to providing adequate chronic health care services in LMICs found that resource constraints for health care generally and chronic disease care specifically was a common challenge [3]. For example, less donor funding is earmarked for NCDs compared to infectious diseases and acute care. Also a weak medicine supply system means medicines are not always available in time or are distributed and stored incorrectly leading to wastage which makes it difficult for patients to uphold long term care of a disease. In Uganda, government provided health services for NCDs are often underfunded and medicines are often unavailable, forcing patients to purchase more expensive drugs from other providers or seek herbal medicines for their chronic illness [35]. Many LMICs do not have an effective and coordinated data collection system that could be used to gain information for planning appropriate treatment with limited resources. LMICs often also have a scarcity of trained health personnel or health workers are concentrated in urban areas, and working in under-resourced and under-paid settings

contributing to low staff retention levels. In South Africa, a systematic review of health worker motivation found that a lack of basic supplies and poor infrastructure affected their confidence and ability to deliver appropriate care to patients [47]. These tangible barriers to health care provision can result in inadequate health services being provided which may in turn discourage patients from seeking and continuing care and lead to people disengaging from formal health care.

Tangible and Intangible Software influences over patient empowerment

Apart from a lack of finances, health workers, and medical supplies, there are also software factors that influence health service delivery that are less easy to see and influence. Tangible software challenges of relevance to chronic care in LMICs include the hierarchal decision making within health systems that does not allow for meaningful input from patients and communities [3]. For example, South Africa, a country with comparatively more financial resources and access to medicines than other LMICs, has a history of weak and centralised leadership that has undermined health service delivery [23]. In contrast, the systematic review on factors affecting CCM implementation [14], as well as interviews exploring organisational factors affecting patient-centred intervention implementation across a variety of health care workers, leaders, and contributors in the United States [48], found that having stable, committed, active and engaged leaders that are able to effectively communicate a vision and get staff on board, were important factors to implementing CCM and patient-centred care in a range of different facilities. Complex and slow bureaucracies, with little coordination amongst staff, are another feature of tangible software. An ethnographic study conducted in the United States and United Kingdom on experiences of self-injection for chronic diseases during a hospital stay found that the division of labour between different health professionals was a key barrier in facilitating patient empowerment [49]. The systematic lack of communication and collaboration between doctor,

nurse, and health care leaders meant that health professionals were often unaware of the work load of the other and so may prescribe different, opposing, or restricted treatment options for the patient. These inefficient leadership and organisational processes then inhibit the ability of health facilities to provide high quality services.

Intangible software factors that affect health facility processes include whether staff feel valued and motivated to provide quality services. A systematic review of health worker motivation in LMICs found that one of the most important factors that motivated health staff was whether they felt appreciated by their managers, received recognition for work well done, and were trusted by other health workers and their community to provide care [47]. 2009 and 2012 assessments of the South African health system, for example, have suggested that after many broken promises from health care leaders and protests from health care providers, there is little trust and communication between government leaders and health service implementers. This has affected the possibility of implementing future policies, as there is little motivation, shared vision, and cooperation between levels of care – regardless of access to resources [23,50]. Similarly, a case study of two South African hospitals explored the role that organisational trust and organisation culture played in policy implementation [51]. The study found that when a facility had high levels of trust between front-line workers and organisation leaders then there was less resistance to new policies from staff. Organisational culture, understood as the underlying values and assumptions that connect people within an organisation, can also lead to greater commitment of staff to policy implementation when underlying values such as cohesion and participation are aligned with policy goals.

In supporting any new policy or programme's implementation it is, therefore, important not only to address resource constraints but also to consider the thoughts, feelings, organisational mindsets, and values that affect how policy and services are actually delivered. Considering these

software factors can enhance health workers' motivation and commitment to provide patient-centred quality care, including spending more time on empowering patients to care for their chronic disease [52]. Providing better quality services is, in turn, likely to elicit trust and engagement from potential patients. These organisational software factors, then, have relevance for bringing about the sorts of changes in chronic disease care that international models such as CCM suggest are needed.

Summary

This narrative literature review has scoped out concepts and experiences relevant to the future of chronic care in LMICs. Currently, health care systems globally largely favour care of acute diseases. Alternative models, such as the Chronic Care Model and the Innovative Care for Chronic Conditions framework, show, however, possible ways forward in strengthening chronic disease care for health systems around the world. Within these chronic care models, self-management development and having an empowered patient are highlighted as key elements supporting improvements in health outcomes over the long term.

There are, however, multiple influencing factors that influence the ability of a patient to achieve a sense of empowerment in relation to their health care. Firstly, patient characteristics influence the willingness of a person to seek and continue care. In LMICs, patient engagement with care is often dictated by poverty levels, education levels, and gender; women and those that are poor or uneducated commonly face the greatest barriers to taking control of their chronic health. Secondly, health system characteristics affect provider attitudes and actions towards patients and so how willing and able patients are to engage with the health system and their care. These include more tangible elements such as levels of finance, others resources, and leadership practices, as well

as intangible elements such as patient-provider trust, whether patients feel validated and health professionals' communication practices.

Justification for further research

The rich literature on chronic care and the role of patient empowerment clearly shows that features of the specific setting in which chronic care is offered have a significant influence over service effectiveness. Therefore, chronic care interventions, such as those promoting patient empowerment, need to consider what patient and health system characteristics in specific settings may act as constraints or enablers of empowered patient-provider relationships. This is particularly crucial in settings with tight resource constraints that cannot afford to implement unacceptable and ineffective changes to care. Research into new forms of chronic care intervention in South Africa is useful as it can help to inform wider action to improve chronic care across the country.

References

1. Habib SH, Saha S. Burden of non-communicable disease: Global overview. *Diabetes & Metabolic Syndrome*. 2010; doi:10.1016/j.dsx.2008.04.005.
2. Hofman K. Non-communicable diseases in South Africa: A challenge to economic development. *South African Medical Journal*. 2014; doi:10.7196/SAMJ.8727.
3. Samb B, Desai N, Nishtar S, Mendis S, Bekedam H, Wright A, et al. Prevention and management of chronic disease: A litmus test for health-systems strengthening in low-income and middle-income countries. *The Lancet*. 2010; doi:10.1016/S0140-6736(10)61353-0.
4. Alwan A, MacLean DR, Riley LM, d'Espaignet ET, Mathers CD, Stevens GA, et al. Monitoring and surveillance of chronic non-communicable diseases: progress and capacity in high-burden countries. *The Lancet*. 2010, doi: 10.1016/S0140-6736(10)61853-3.
5. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D. The burden of non-communicable diseases in South Africa. *The Lancet*. 2009; doi:10.1016/S0140-6736(09)61087-4.
6. Goudge J, Gilson L, Russell S, Gumede T, Mills A. Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 2009; doi:10.1186/1472-6963-9-75.
7. Norris SL, Engelgau MM, Venkat Narayan KM. Effectiveness of self-management training in type 2 diabetes. *Diabetes Care*, 2001;24:561-587.
8. World Health Organisation. Global status report on non-communicable diseases 2014. Geneva: WHO Press; 2014.
9. Allotey P, Reidpath DD, Yasin S, Chan, CK, Aikins A. Rethinking health-care systems: A focus on chronicity. *The Lancet*, 2010; doi: 10.1016/S0140-6736(10)61856-9.
10. Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the Chronic Care Model in the new millennium. *Health Affairs (Milwood)*, 2009; doi:10.1377/hlthaff.28.1.75.
11. Holman H, Lorig K. Patients as partners in managing chronic disease. *BMJ*, 2000;320:526-7.
12. United Nations University. Pascale Allotey. n.d. <https://iigh.unu.edu/about/the-team/pascale-allotey#overview>. Accessed 14 Mar 2018.
13. Epping-Jordan J, Pruitt S, Bengoa R, Wagner E. Improving the quality of health care for chronic conditions. *Quality & Safety in Health Care*. 2004; doi:10.1136/qshc.2004.010744.
14. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, Brown A. Factors influencing the implementation of chronic care models: A systematic literature review. *BMC Family Practice*. 2015; doi:10.1186/s12875-015-0319-5.
15. Bodenheimer T. Interventions to improve chronic illness care: Evaluating their effectiveness. *Disease Management*. 2003;6:63-71.
16. Anderson RM, Funnell MM. Patient empowerment: Myths and misconceptions. *Patient Education and Counselling*. 2010; doi:10.1016/j.pec.2009.07.025.
17. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*. 2006; doi:10.1016/j.pec.2006.09.008.
18. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M, et al. Conceptualising patient empowerment: A mixed methods study. *BMC Health Services Research*. 2015; doi:10.1186/s12913-015-0907-z.
19. Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*. 2016; doi:10.1016/j.pec.2016.07.026.
20. McAllister M, Dunn G, Payne K, Davies L, Todd C. Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Services Research*. 2012; doi:10.1186/1472-6963-12-157.

21. Korytkowski MT, Koerbel GL, Kotagal L, Donihi A, DiNardo MM. Pilot trial of diabetes self-management education in the hospital setting. *Primary Care Diabetes*. 2014; doi:10.1016/j.pcd.2013.11.008.
22. Maybrey ME, Setji TL. Patient self-management of diabetes care in the inpatient setting: Pro. *Journal of Diabetes Science and Technology*. 2015; doi:10.1177/1932296815590827.
23. Chopra M, Lawn JE, Sanders D, Barron P, Abdool Karim SS, Bradshaw D et al. Achieving the health Millennium Development Goals for South Africa: Challenges and priorities. *The Lancet*. 2009; doi:10.1016/S0140-6736(09)61122-3.
24. Shah AD, Rushakoff RJ. Patient self-management of diabetes care in the inpatient setting: Con. *Journal of Diabetes Science and Technology*. 2015; doi:10.1177/1932296815586581.
25. Stanhope V, Henwood BF. Activating people to address their health care needs: Learning from people with lived experience of chronic illnesses. *Community Mental Health Journal*. 2014; doi:10.1007/s10597-013-9686-3.
26. Kardas P, Lewek P, Matyjasczyk M. Determinants of patient adherence: A review of systematic reviews. *Frontiers in Pharmacology*. 2013; doi:10.3389/fphar.2013.00091.
27. Mackian S, Bedri N, Lovel H. Up the garden path and over the edge: Where might health-seeking behaviour take us? *Health Policy and Planning*. 2004; doi: 10.1093/heapol/czh017.
28. Peters DH, Garg A, Bloom G, Walker DG, Brieger WR, Rahman H. Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences*. 2008; doi:10.1196/annals.1425.011.
29. Rubin DJ, Donnell-Jackson K, Jhingan R, Golden SH, Paranjape A. Early readmission among patients with diabetes: A qualitative assessment of contributing factors. *Journal of Diabetes and its Complication*. 2014; doi:10.1016/j.jdiacomp.2014.06.013.
30. Ek S. Gender differences in health information behaviour: A Finnish population-based survey. *Health Promotion International*. 2013; doi:10.1093/heapro/dat063.
31. Abubakar A, Van Baar A, Fischer R, Bomu G, Gonaz JK, Newton CR. Socio-cultural determinants of health-seeking behaviour on the Kenyan coast: A qualitative study. *PloS ONE*. 2013; doi:10.1371/journal.pone.0071998.
32. Shaikh BT, Hatcher J. Health seeking behaviour and health service utilization in Pakistan: challenging the policy makers. *Journal of Public Health*. 2004; doi:10.1093/pubmed/fdh207.
33. Wang Q, Brenner S, Leppert G, Banda TH, Kalmus O, De Allergri M. Health seeking behaviour and the related household out-of-pocket expenditure for chronic non-communicable diseases in rural Malawi. *Health Policy and Planning*. 2014; doi:10.1093/heapol/czu004.
34. McIntyre D, Thiede M, Dahlgren G, Whitehead M. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? *Social Science and Medicine*. 2006; doi:10.1016/j.socscimed.2005.07.001.
35. Hjelm K, Atwine F. Health-care seeking behaviour among persons with diabetes in Uganda: An interview study. *BMC International Health and Human Rights*. 2011; doi:10.1186/1472-698X-11-11.
36. Kazaura MR, Kombe D, Yuma S, Mtiro H, Mlawa G. Health seeking behavior among cancer patients attending Ocean Road Cancer Institute, Tanzania. *East African Journal of Public Health*. 2007;4:19-22.
37. Masupe TK, Ndayi K, Tsolekile L, Delobelle P, Puoane T. Redefining diabetes and the concept of self-management from a patient's perspective: Implications for disease risk factor management. *Health Education Research*. 2018; doi:10.1093/her/cyx077.
38. Harris B, Goudge J, Ataguba JE, McIntyre D, Nxumalo N, Jikwana S, et al. Inequities in access to health care in South Africa. *Journal of Public Health Policy*. 2011; doi:10.1057/jphp.2011.35.
39. Peer N, Steyn K, Lombard C, Lambert EV, Vythilingum B, Levitt NS. Rising diabetes among prevalence among urban-dwelling black South Africans. *PloS One*. 2012; doi:10.1371/journal.pone.0043336.
40. Willems S, De Maesschalck S, Deveugele M, Derese A, De Maeseneer J. Socio-economic status of the patient and doctor-patient communication: Does it make a difference? *Patient Education and Counseling*. 2005; doi:10.1016/j.pec.2004.02.011.

41. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient–physician communication during medical visits. *American Journal of Public Health*. 2004; doi:10.2105/AJPH.94.12.2084.
42. Mercuri M, Sherbino J, Sedran RJ, Frank JR, Gafni A, Norman G. When guidelines don't guide: The effect of patient context on management decisions based on clinical practice guidelines. *Academic Medicine*. 2015; doi:10.1097/ACM.0000000000000542.
43. Schlemmer A, Mash B. The effects of language barrier in a South African district hospital. *SAMJ*. 2006;96:1084-7.
44. CHEPSAA. Recognising agents in health systems ... and complexity. 2015. https://www.slideshare.net/hpsa_africa/recognising-agents-in-health-systemsand-complexity. Accessed 01 May 2018.
45. Sheik K, Gilson L, Agyepong IA, Hanson K, Ssengooba F, Bennett S. Building the field of health policy and systems research: Framing the questions. *PLoS Medicine*. 2011; doi: 10.1371/journal.pmed.1001073.
46. Ellokori S, Olckers P, Gilson L, Lehmann U. Crises, Routines and Innovations – the complexities and possibilities of sub-district management. In: Padarath A, English E, editors. *South African Health Review*. Durban: Health Systems Trust; 2013. p. 161-173.
47. Willis-Shattuck M, Bidwell P, Thomas S, Wyness L, Blaauw D, Ditlopo P. Motivation and retention of health workers in developing countries: a systematic review. *BMC Health Services Research*. 2008; doi:10.1186/1472-6963-8-247.
48. Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*. 2011; doi:10.1093/intqhc/mzr024.
49. Schiff M, Saunderson S, Mountian I, Hartley P. Chronic disease and self-injection: Ethnographic investigations into the patient experience during treatment. *Rheumatology and Theory*. 2017; doi:10.1007/s40744-017-0080-4.
50. Mayosi BM, Lawn JE, van Niekerk A, Bradshaw D, Abdool Karim SS, Coovadia HM, et al. Health in South Africa: Changes and challenges since 2009. *The Lancet*. 2012; doi:10.1016/S0140-6736(12)61814-5.
51. Erasmus E, Gilson L, Govender V, Nkosi M. Organisational culture and trust as influences over the implementation of equity-orientated policy in two South African case study hospitals. *International Journal for Equity in Health*. 2017; doi:10.1186/s12939-017-0659-y.
52. Blaauw D, Gilson L, Penn-Kekana L, Scheider H. Organisational relationships and the 'software' of health sector reform. 2003. https://www.researchgate.net/publication/250845181_Organisational_Relationships_and_the_'Software'_of_Health_Sector_Reform. Accessed 03 Jun 2018.

PART C: JOURNAL MANUSCRIPT

Note to examiner: The manuscript reports on exploratory work conducted to identify factors influencing patient experience of chronic care in a hospital setting. As the planned intervention was not implemented by the time of this study, it was not possible to conduct an evaluation of the intervention as initially proposed (see Part A). The work conducted was, however, fully within the parameters of the protocol and the related ethics clearance. It was broadly equivalent to phase one of the work proposed.

Factors that influence patient empowerment in inpatient chronic care:

Early implementation experience with a diabetes care intervention in

South Africa

Nina Abrahams¹

Targeted Journal: BMC Health Services Research²

Abstract

Background: The burden of non-communicable diseases is growing rapidly in low- and middle-income countries. Research suggests that health interventions that aim to improve patient self-management and empower patients to care actively for their disease will improve health outcomes over the long term. This paper reports a small scale, exploratory study that sought to understand what factors in patients' personal lives and in the health system affect their feelings of empowerment in relation to their chronic disease care, and to provide recommendations for future inpatient-based interventions to support self-management of disease.

¹ For the purpose of this thesis, the student is the sole and first author of the work.

² Instructions for authors in appendix E.

Methods: This study was based in an academic hospital in South Africa. Eighteen semi-structured interviews were conducted with multiple stakeholders in diabetes care; inpatients, health professionals, and academic staff. Findings were analysed using a thematic approach, and broadly guided by a realist paradigm.

Results: Interviews with both patients and providers suggest that patients living in low socio-economic contexts are likely to struggle to access appropriate healthcare information and services, and may often have financial and emotional priorities that take precedence over their chronic illness. Younger people may also be more dependent on their family and community, giving them less ability to take control of their disease care and lifestyle. In addition health care remains bound by an acute care model; and the inpatient setting of focus is characterised by perceived staff shortages and ineffective communication that undermine the implementation of patient empowerment-focused interventions.

Conclusions: Patient and provider contexts are likely to make supporting patient engagement in long term chronic care difficult. However, knowledge of these factors can be harnessed to improve chronic care interventions in South Africa, and other low- and middle-income countries.

Keywords: Non-communicable disease; inpatient, empowerment; diabetes; South Africa; qualitative

Background

Estimates predict that by 2030 non-communicable diseases (NCDs) will account for five times as many deaths as infectious diseases in low- and middle-income countries (LMICs) and that 80% of global death from NCDs will occur in these countries [1,2]. The World Health Organisation (WHO) estimates that in 2004 NCDs were the cause of nearly one-third of the burden of disease in South

Africa and that this burden is two to three times the burden experienced in developed, high-income countries [3]. Compared to 23 other LMICs, South Africa has the third highest death rate due to NCDs per 100 000 adults – with cardiovascular disease and diabetes serving the largest load [4]. This growing burden of NCDs not only results in ill-health for individuals but also places a large social and economic strain on families, communities, and the country. Between 2006 and 2015 diabetes, stroke, and coronary heart disease alone cost South Africa nearly two million American dollars in gross domestic product losses [1]. Additionally, as NCDs are often long term and result in increased illness and disability, employers are faced with increasing staff turnover and absenteeism and families face long term medical expenses as well as losing their main income earners. In spite of this, South Africa's health system is still largely geared towards infectious diseases such as HIV and TB, marginalising research and services capable of preventing and treating NCDs [3,5].

International research into chronic care strategies highlights self-management and patient empowerment as important elements of effective chronic care [6-11]. This is due to the fact that chronic diseases are long term and people need to learn to manage, adapt and take control of caring for their disease long after visiting a health professional. In light of this, an academic hospital in South Africa is looking to introduce an intervention for inpatient diabetes care of which one of the elements seeks to support patients to self-manage their disease and to empower patients to continue their care once they are discharged from the hospital. The intervention would involve a multidisciplinary team including medical staff, administration, laboratory, and quality improvement stakeholders in order to revise and simplify current medication administering and recording systems, improve the nutritional value of food given to patients while hospitalised, and improve patient education and self-management training. This intervention is seen as more cost-effective than repeated periods of inpatient care and as lessening the resource burden on both the health system and the patients themselves.

This paper considers what factors in patients' personal lives and in the health system influence whether patients feel empowered to self-manage their chronic disease once they leave a hospital setting. It then draws out lessons for future inpatient empowerment interventions to consider in their design and implementation.

Methods

Setting, sampling and data collection

This study was conducted in a major academic hospital South Africa. Eighteen participants were purposively sampled based on whether they had knowledge of the inpatient diabetes care provided at the hospital. Participants were then grouped into three categories: six health professionals who were charged with improving inpatient empowerment in diabetes care (A), five health professionals who were primarily responsible for engaging with patients and have experience of caring for people with diabetes in the hospital (B), and seven people who have diabetes and have also experienced being an inpatient in the hospital (C). Thirteen participants were female but all participants ranged widely in race, age, and time spent at the hospital.

Potential participants were identified by leaders in the hospital's endocrinology department. These participants were then approached by the primary researcher and in-person or via email given an information leaflet that indicated the purpose and method of the study, inviting them to be interviewed. If they agreed, informed consent was obtained and interviews were conducted at a time and place that suited the participant. Interviews were semi-structured using questions that, drawing from wider literature on chronic care and empowerment, sought to elicit the experiences and thoughts of respondents on current inpatient practices and chronic care. Questions were further refined after the first few interviews were conducted. During interviews, participants were

asked their opinion on issues raised by other participants in order to cross-validate information and increase rigour of the findings [12,13]. Sixteen of the interviews were conducted in English and two in isiXhosa using a translator. Interviews varied in length between 20 minutes and one hour. Interviews were recorded, transcribed and anonymised by the primary researcher.

Approval for this research was obtained through the Human Research Ethics Committee of the University of Cape Town (HREC: 484/2017) as well as through the Western Cape Health Research Committee and hospital under review.

Data analysis

The analysis took an exploratory approach which is useful in generating theory and finding out what is happening in little understood situations [12]. The themes and codes used in analysis were initially identified by the primary researcher, and then validated by the supervising researcher in order to strengthen the rigour of the analytic process [12]. A realist perspective broadly guided this exploratory work, in that the researcher recognised that while experiences are personal and variable there are certain broad truths or mechanism that can explain behaviour within particular contexts [14,15]. Considering the small-scale of the study the analysis was focussed on gaining an initial picture of the contexts and mechanisms of behaviour that explain patients' ability to feel sufficiently empowered to care actively for their chronic disease; with findings also situated within relevant, existing literature.

Results

The experiences of participants were categorised into two broad themes. The first theme considers what contexts of patients' own lives may affect the way they are able to engage in their diagnosis and care. The second theme explores what aspects of inpatient care affect the ability of health

services to strengthen patients' feeling of empowerment in caring for their chronic disease. The links between these two themes are also explored.

Socio-economic status and the ability of patients to engage in their own care

Five of the patients interviewed were young, in their 20s or early 30s, and had very recently, within the last month, been diagnosed with diabetes, while two of the patients were in their forties and had been living with diabetes for over ten years. All the patients had family or friends with diabetes and so, while the newly diagnosed patients were often nervous about the disease, its medication, and the lifestyle changes that would need to take place, they were still quite confident that they understood the disease and were surrounded by people who could answer their questions. The two patients who have had diabetes for a long time are now at point where they accept their diagnosis and have made major changes to their lifestyle in order to care for their diabetes.

"Yes that's why it's easy to me, why I accept it. I accept easy because my family has diabetes." [C3]

However, the wider context of poverty, and how this affects the family and community of the patients, illuminates what influences patients to follow appropriate lifestyles, engage in chronic health care, and take up the advice of health professionals. All the patients came from low- to middle-income communities which affected the way they are willing and able to engage in health care. Firstly, while patients were comforted by the fact that they were surrounded by others who had diabetes, advice and support from others were often misinformed and ineffective. This, in turn, resulted in patients engaging in inappropriate care or being discouraged from seeking formal health care while attempting to navigate the misinformation of peers.

“At the beginning I was not that confident because people were saying you are going to be cut, so I was like okay let me just keep my mouth shut and listening, what must I do now ... Yes, sometimes, like negative. ‘If you have diabetes you’re going to be cut’ ‘It’s better to have HIV than that’. In the clinic I was quiet and sit there in the corner, people talking. I feel like I’ve got this disease that is normally in the old people, now I’ve got this disease like I did something wrong, what did I do now?” [C2]

“They are afraid if they tell the girlfriend they might be dropped, because mostly the partner doesn’t have an understanding onto diabetes so they see it as something contagious which it’s not, so they don’t mention it. The other problems is they don’t want to stay away from work [and come to appointments] because they might lose their jobs, and they don’t want people at work to know they are diabetic.” [B1]

In addition, the relatively low socio-economic status (SES) of these patients meant that they were often unable to access appropriate information and care even if they did become aware of the misinformation surrounding them. This was in part due to their communities having less access to appropriate services as all the patients reported that clinics were often far away or health providers were perceived to be not of high quality in poorer areas. Patients’ low SES also meant that they struggled financially to get to better health care services. Only one participant had a job and felt financially secure, two had to resign from their jobs while inpatients in the hospital, the others relied on their family or a social grant to be able to afford health care appointments,

transport, and equipment such as a glucose meter. This meant that health care was often not a priority compared to other financial burdens.

“The two main issues that stops [patients] engaging in primary care. The first one is their social situation, there are far more important things in their life like ‘where do I get my next job from, my son is a drug addict, there’s no food on the table, what am I going to do?’” [A2]

“Food insecurity is a huge issue in our setting. Crime huge issue, their monitor is being stolen, their medication is being stolen, being mugged, going to the day hospital is often dangerous. So it’s a huge challenge.” [A6]

“I think communication is one of our biggest problems, so sometimes it’s not carried over the way it’s supposed to be. I get information and I understand it so its fine with me but sometimes there’s people that’s never went to school, or sometimes you’re sitting with people with challenges and they sitting here for so long and you explain to them and then they say they can’t see because they have been affected, their eyesight. I say do you wear specs and they say no I’m still waiting on it, something from the eye department or that thing.” [B1]

Two participants relayed their experience of the health care referral system. One participant struggled to get referred to tertiary care and felt that her primary care providers did not give her enough attention and time to understand fully her health problems. When complaining of incessant pain her clinic continued to prescribe the same medicines that she had tried multiple times. Each clinic visit she begged the clinic staff to provide a hospital referral since all the medication she had

tried was not helping and she could only book an appointment to see a hospital doctor months in advance, but she was continuously refused. She eventually got admitted to the hospital after her pain became unbearable.

“March I went to the clinic again, they gave me the same thing, I said I’m not going to take these tablets. Look at my folder you will see how many these tablets I’ve tried, the only thing I want is a letter so I can go to the hospital. They refused; say I must make an appointment. So on Friday I was going to work and I can feel I am weak, my heart said I must not go to work and I followed my heart. I went to hospital and that was the day I was admitted”. [C7]

On the other hand, when another patient complained of severe symptoms to her local diabetes club, she was immediately referred and hospitalised.

Therefore, the availability of appropriate financial and economic support affects in what ways a patient is able to act and how much a person is able to prioritise caring for health over a long term as with a chronic illness.

“A very empowered patient, if there’s nothing that you’ve got to eat and at the second day of not eating you get given a chocolate you eat the chocolate, it doesn’t matter how empowered you are.” [A6]

The setting of low SES, misinformation, and inadequate healthcare access also significantly affected the younger patients. In this research all the younger patients still lived with their immediate family – likely due to financial dependence and social norms. This meant they were all highly influenced by family norms and tended to follow family behaviour more than the older,

independent patient. All the young patients mentioned the difficulty of their family preparing and eating tempting but unhealthy foods in front of them, and how this made it more difficult to adhere to their diet plans. Three patients as well as two health professionals revealed that patients do not like feeling different to others, as when eating other foods and pricking their finger; and did not like feeling like they could not engage in fun but relatively unhealthy activities, with their peers.

Comparatively, one of the older patients, who now headed her household and has more independence, personal income and life experience, was able to control better what others in her house ate, and encouraged those in her family to eat more healthily and engage in healthier lifestyle activities.

Several health professionals and patients reported that young people in this low SES setting can be additionally burdened with a sense of helplessness over future financial stability and potential employment. These frustrations often present themselves in defiant and dismissive behaviour towards health care. One of the older patients commented that when he was younger he chose to ignore the health advice that he received and, as a result, now feels he has worse health outcomes.

"[Insulin] changed my life. I had a nice time life. Drinking, partying, eating, braaing, everything demarkaar [all over the place]. It changes my whole life. I had to stop everything. All the parties, all the drinking, the braaing, the meat eating, chicken, everything stopped. And I had to go home and I had to go lick my wounds until today I'm still licking my wounds."
[C6]

"Then you find that there is one person that is working and feeding five or six people. So a lot of depression out there. In the young adult clinic there's a sense of hopelessness about jobs."

They sit around at home, they are isolated they are alienated they don't have friends in the neighbourhood. It's a really hard actually. We need much more social support. It's a lonely business." [A5]

Two health care professionals found that younger people are less compliant to authority, take more health risks, and have less commitment to long term care - and therefore engage less in treatment plans that aim to improve their health.

"But the thing is mostly young people, in their teens and early 20s. And they are the group that's usually unfortunately uncompliant. They do not take medication, they do not rock up for appointments, they always have one or another excuse, but luckily for them they don't hide around the bush, they tell you exactly what their problem is." [B1]

The dependence of young patients on families also added complexity to their health care engagement. Two health professionals emphasised the importance of including family and peers in the diabetes education of the patient – in order to increase household education levels on chronic care and so develop patient support systems that understand and support them in their lifestyle change. However, another health professional warned that including family in the patient's treatment plan can discourage young patients from taking an active and enthusiastic role in their care, as some families try to take control of appointments, assuming patient naivety and dependence, and then micro-manage how the patient engages with their care. Patients may, then, be tempted not to share their diabetes status with others in fear of being reprimanded when 'cheating' on their diet or lifestyle.

"[The patient] refuse to come to the clinic because [the doctors] have access to their mother at home, and their mother constantly when he comes here will reprimand him and he couldn't handle it." [B1]

Despite these circumstances of low SES and unsupportive community norms, there are a few factors that helped motivate the patients to engage in their chronic care. As mentioned before, the older patient who had more financial dependence had a greater influence on the behaviours of those around her and so could encourage others to follow a healthier lifestyle, also making it easier for her to follow it. All the young patients mentioned that being surrounded by appropriate support systems was helpful. This includes being surrounded by others with diabetes who can help them understand and accept their disease and who can answer their questions. Two patients who were part of diabetes clubs in their local areas commented on the clubs' usefulness for education, advice, and medical care access.

"He didn't really have problem, especially when he noticed that he is not the only one at his age, he has peers that are also diabetic." [C4]

Similarly, patients were motivated to care for their chronic disease when they were an important source of support for others. Four of the patients drew motivation from their children as they wanted to be around and healthy in order to see their children and grandchildren grow. Three of the patients mentioned that the shock of experiencing adverse symptoms or seeing others experience these events, especially those that resulted in hospitalisation, helped them understand how serious their diagnosis was and how necessary it is to heed health advice continually.

“The more I learnt, especially when I got sick it actually made me realise this is not something you must play with or ignore.” [C1]

One health professional mentioned that when patients have high levels of resilience then they are able to overcome many of their health care barriers.

“So there’s the person and then there’s where they live and it’s the interaction between the two, and there’s resilience and there’s ability to cope, there’s support. They all play out differently.” [A5]

Health providers and the inpatient setting

The hospital setting, namely short-term inpatient care for sick patients, offers a particular set of circumstances that affect the way health providers are able to engage with patients and patients are able to engage in health care. Firstly, the nature of hospitalisation means that patients are particularly sick during this time. Patients may be hospitalised for a variety of reasons and not just due to the direct effects of their diabetes, as there are high rates of multi-morbidity in chronic disease. Therefore, in this setting, patients are less likely or able to engage with health professionals as they are usually in a more vulnerable state than normal and so cannot retain a lot of new, long term, lifestyle-changing information. Three health professionals reported that it becomes difficult to engage well with patients when they are in the inpatient setting, as patients may be unable to speak, they may struggle to retain educational information, or they may be physically unable to give themselves medicine or make informed decisions about food. Some patients also noted that they were distracted by how they were going to afford their health care costs, especially considering that they were unable to work while in hospital.

Given how sick and unengaging patients can be during hospitalisation periods, health professionals judge it necessary to control most aspects of the patient's life in hospital in order to control and treat adverse events. Therefore, the time in the hospital does not usually reflect behaviours in the real world setting. Three patients in the study described how the hospital does not represent real life - such as receiving all meals ready-made and eating at times that suit the resources and convenience of the hospital. They also mention undergoing intense medical procedures and the difficulty of sleeping amongst tubes and hospital sounds. This 'false' setting then makes it increasingly difficult for them to implement what they have learnt in the hospital when back in the home context.

"Of course when patients are admitted to the ward they are completely disempowered. That's how hospitals work. You take all their rights away, you take all their privileges away. You even take their clothes away and give them a funny white blue gown where their bum sticks out. You know they are completely disempowered and they have almost no say in what happens to them. Some patients are quite strong and will demand something and some patients will be quite passive but generally we disempower them completely and then we carry on and look after them and then let them go." [A2]

Inpatient staff, meanwhile, find that because of the usually short-term care and the rush to treat a patient that there is little time to provide relevant education and allow for patient independence in their care, even if the patient is relatively healthy, aware, and has time while waiting in hospital. This situation is exacerbated by what is perceived as a shortage of staff, in that health professionals find they do not have the time to train, watch, and retrain patients in their own care. One nurse mentioned that even if she gave patients more autonomy, the final

responsibility rests with her if something goes wrong and so it is easier to take control of the patient and guarantee they are receiving the necessary treatment.

“It’s inpatient, so the patient is totally dependent on us as nursing staff. We do the blood glucose checking, insulin we give ourselves. We had times when people were taking their own insulin but their glucose don’t come down or they just shoot up. They don’t do the insulin correctly so the nursing staff we do everything for the patient, as an inpatient the patient is our responsibility ... The insulin is kept in the fridge and the needles is kept with us, you know with medical and legal hazards so it’s better if we give it.” [B3]

“The doctor has maximum 6 minutes to see the patient. That includes in the 6 minutes everything that the patient wants to talk and discuss, reviewing the patient, checking their feet and eyes, doing blood tests, writing up forms, doing a blood test, all that stuff. So in fact nothing happens because there’s just not enough time... There is a lot of potential contact hours, other than the 6 minutes and [the doctor is] gone. [The patient is] in the hospital for many many hours, 5 days 6 days, so there’s lots of opportunity for contact time”. [A2]

As a training institution, the hospital also has particularly high levels of staff turnover.

Health professionals are often on rotation across different parts of the hospital, whilst support from new graduates disappears when examinations are in progress and trainees often move on from the institution once their training is complete. As a result it is difficult to create coherent teams with good communication and constant training and short-term staff can be disinterested in becoming familiar with new protocol and guidelines.

“The first thing is getting buy-in from everybody, making sure everyone is educated. It’s actually quite hard, partly because the staff rotate all the time. Our nursing staff, 40% are locum staff, they don’t belong to the hospital, they don’t care about the hospital, they just here to do a shift and then leave, they don’t have a clue what’s going on, they find a new form no one told them because they’re just here for one shift. The doctors rotate every three months, depends on where you catch them. So you have this constant staff turnover.” [A2]

Three respondents recognised that the controlling nature of the inpatient setting, coupled with staff-shortage and turnover issues, means that health professionals can become inflexible, rushed, and rude to patients. This can, in turn, create resistance from patients, as they feel they are not being given attention nor being offered holistic care. Providers can then be forced to juggle between the rules of the hospital and the need to treat and discharge a patient, with the need to consider a patient as a whole being with history, knowledge, and circumstances that may affect their long term care. One patient relayed her experience of dealing with a rude doctor who argued that he was the health expert and so would not listen to her when she felt she was not getting the right dose of insulin.

“He said okay I give up. Before he said that he pointed his finger at me and said ‘as long as you are in this hospital you are not going to refuse this’ I am the one who is diabetic, I have experiences... This is my body; I’ve been diabetic for 20 years. I know what is right and what is wrong. I may not be a doctor but I know about diabetes, I learn in in the clinic about diabetes, I got to clubs. So I know what I’m talking about.” [C7]

While often easier for health professionals to take control of patients while in the inpatient setting, this *“treating patient like a baby” [B1]* approach, can result in negative long term effects. One health professional complained that in the time between patients being discharged and returning for a follow up appointment, they have often not correctly used their medicines because they were not adequately trained and empowered during their inpatient stay. Another health professional admitted that this controlling approach can dampen a patient’s ability and enthusiasm to do things for themselves, resulting in poor health outcomes post-discharge.

“It is like just, humanly, when you are in hospital ‘yes doctor, yes doctor’ while you here but the moment you are out the door...” [A3]

“I think sometimes they don’t feel like going home, because sometimes they feel they going to be, not that they going to be neglected, but I mean here they being cared for, take the tablets, and washed. Now they scared to go home because they scared to keep up, to take their tablets on time and make sure that they eat before they take their tablet.” [B2]

Patients are also often not adequately supported after leaving the hospital and so struggle to continue to follow the health advice of doctors and nurses. Three health professionals noted that it is important to get patients out of, and less dependent on, hospital services as the hospital is currently overbooked and is also not a healthy place to be for long periods. However, often referral letters are not filled in correctly or primary facilities are over-flowing, have long queues, or do not have a referral receiving system and so are not able to give adequate attention and support to referred patients. In addition, patients are not adequately followed up to see if their medication is

actually appropriate in their home setting. Patients therefore have few options for continued support.

“We know from looking at the medicine management that patient compliance is an issue. I think it's really visible when patients pass on because then we get bags of medicines returned by family members and you can see that the patient has been religiously collecting the medicine but not using it...Its continuity of care, no one is actually really following the pathway so we almost relying on the patient to follow that pathway and do what is expected of them.” [A1]

Patient-provider relationship

It is clear that both the context of the patient and the context of the health provider can inhibit their ability to engage actively in long term chronic care. These issues interact in complex ways when the patient and provider engage in the health care setting. For example, three of the health professionals interviewed noted that the low SES context of the patient greatly affects the way they then relate to the patient and the way they end up conducting their work. One health professional explained that some patients take their diabetes medication and equipment and sell them rather than use them, as they are desperate for the finances. This can make health providers more wary and less trusting that patients will heed health advice, perhaps then affecting the way they engage with particular patients. One health professional admitted that providers engage more actively with patients from particular age and income groups whom are assumed to be more capable of taking care of their chronic disease. Two providers explained that they became demotivated to work when dealing with uncompliant and ungrateful patients.

"I think we are sometimes judgemental if a student comes here in tertiary education then we give all the information. Now someone comes from a rural area then we give only certain information which is unfair. We should actually give all information to everybody, what they do with it is their problem, but we sometimes judge people when it comes to that." [B1]

Even though the newly diagnosed patients in the study felt they had received a good amount of education and had been given support and skills from the nurse educators to monitor their medication and diet, and even though they felt committed and enthusiastic about following the health advice given, health professionals are aware that this enthusiasm is difficult to maintain once back in their home environment. One of the older patients noted that it was very difficult to implement doctors' advice back in the real world and when confronted with old habits and inadequate support systems. Two health professionals reported that they end up playing social worker in order to navigate the many needs of a patients and that this can be a heavy emotional burden for them. Considering this, they explained how necessary it is to work closely with other social welfare sectors in order to help their patients as much as possible while also protecting the health provider from getting too involved in patients' lives.

"When it comes to the hospital, I won't say we, it's like we expect for them to give us all information which they are not giving. And we expect sometimes this, we want them to be open and honest but they're just a human being. It's like some, I had a patient that I must educate here, and when I said regarding the insulin 'try with something to eat'. It's no use I'm having all this pamphlets and magazines I'm showing her and then what she said sometimes she needs to go to the neighbour to get something to eat just so she can take her insulin. And I stopped the education immediately and I went to, and what I said is, I asked just to write a note on his memo pad and I referred her to Social Work for a food parcel.

Because sometimes we educate and we educate but forget the circumstances at home."

[B1]

Patients and health providers did however note some important roles that the hospital played in encouraging patient enthusiasm and engagement in long term chronic care. For example, one patient commented that she was feeling confused about the diagnosis but now she understands it and what it means for her life and that it was her visit to the hospital that helped to answer these questions. In addition, as the study hospital under review is better resourced than many other health facilities in the country it can often better provide equipment and medicines to patients. Two patients relayed their experience of being able to access insulin and a glucose meter at the hospital and not elsewhere and how this greatly improved their ability to take control of their diabetes.

One health professional explained that when she went beyond her expected hospital role and was able to make a longer-term connection with the patient and provide them with basic support, then together they were able to overcome many of the barriers of the hospital and home context. She commented that patients participate better in their care when they feel like they are included in, and can take ownership of, the creation and planning of their treatment plan and that patients are more willing to engage in care when they fully understand what the disease is and why they need to go for certain medical procedures. Similarly, another health provider stated that patients may not always admit when they are not following health professionals' advice because they fear that they will no longer receive care but if the health professional can provide the patient with a sense of security, trust, and understanding that it is normal to make mistakes and to struggle to make lifestyle changes then it encourages honest and open patient-provider engagement.

"You not only have to educate but also convince them to want to be educated ... So then, from there I notice, oh okay, that is my first thing to have a bond with them, to win them ... So I just having this close relationship and now I give my number to them, then to say you can phone or whatsapp me anything, even on the weekend as long as it's not 10 at night, which they do. So they put that trust on me quite a lot ... If I am saying there is a need for this close relationship, it's amazing because they get so interested, they come ... So they feel so motivated because at least now they are participating. So all in all, I'm motivating them to participate in the diabetes, I am always telling them that I am with them in their journey ... We keep that relationship so that they don't relapse ... to be in partnership with them, they really like it, which I learnt from psychology ... They feel like having that close relationship." [B5]

Health providers and the health system setting

All providers noted that the way the health system functions, beyond just inpatient care, in itself can make it difficult to provide holistic care for diabetes patients. For example, four health professional explained that health facilities largely work in *"disease silos"* [A2] where patients with different diseases are treated and cared for on an individual disease basis and not holistically. In the hospital under review, providers reported that preference is given to the disease or problem that the person was admitted for; often to the neglect and detriment of other health issues they may have. This makes it difficult for health providers to gain a full picture of patients and their needs and so are often unable to provide the most adequate healthcare. One health professional explained that doctors in different wards can even forget to record diabetes medicine when

discharging patients, forcing patients to return prematurely to the hospital in order to retrieve the correct medication.

“It is a problem because the way the system is designed when you're in a surgical ward for procedures you're being managed for the procedure, so diabetes is not your focus ... we're focusing now on your procedure I'll just continue whatever was done even if it's not appropriate.” [A1]

Another barrier to providing health services is the general lack of funding available. For example, five health professionals mentioned that the budget currently does not allow the hospital to always offer the best and personalised meal plans or the most effective medication. Additionally, there is not enough medical equipment for each patient and there are inadequate monitoring systems in place. These providers mentioned that they had ideas and plans for how to improve patient care but that the hospital could not currently afford it.

The most significant resource constraint felt by providers is what they experience as a shortage of staff. All health professionals and intervention developers mentioned that increased staffing could result in less staff burnout and more time spent giving individualised care to patients. Currently, staff are over-burdened with administrative duties or need to move on to the next patient in order to fit everyone in – losing a valuable opportunity to connect with and uplift patients.

“We have to empower patients to manage themselves. In the state sector, because of the numbers, I mean our waiting list at the diabetes clinic is about 6 months. If you are a diabetic, you are going to get to see me twice a year ... That's two hours a year if you're in

the best medical scheme you're allowed to see your doctor. The rest of the time you're on your own". [A6]

"What she also mentioned to me, which I wasn't happy with, I asked 'do you tell the doctor all these things?' she said 'I would have but the doctor was in a hurry'". [B1]

All the nurses explained that the shortage of staff and their long hours put a strain on their ability to give patients quality care and leave them feeling tired and demotivated to work. In addition, they then could not gain the gratification of seeing patients improve and neither had the energy to lobby for better hospital processes or attend extra training workshops. They explained how over the years there has been a growing number of patients and that they are unable to handle the increasing workload. Yet as the frontline workers who interact most with patients, they are still expected to take full responsibility for all aspects of patient care – beyond levels they felt were reasonable given the hospital and health system constraints.

"Six nurses for a whole ward of 30 patients, with walls in between. We can't see behind that wall what that patient is doing, but management asks 'where are the nurses?' So six nurses must now cut themselves, put my arm there, my head there then at least every part will look at the patients ... My daughter said she wants to be a nurse I said 'no baby, no way, mommy's saving money for you, you must go study for something else but not a nurse, it's not worth it.'" [B3]

Health providers are not only influenced by resource constraints but also, in many less obvious ways, by the bureaucracy, institutional habits, and relationships of the hospital. Three

health professionals mentioned issues such as staff having multiple roles and obligations and so little time to dedicate to creating and implementing new interventions that could potentially improve hospital processes. All the health professionals also experienced problems with what they perceived as the ineffective ways in which information, such as new protocols or new expectations from leadership, is shared amongst staff members, and how clashing and changing information often creates confusion among staff and resistance, for example to implementing the proposed diabetes intervention. In addition, older health professionals who had been working for a long time found that providers often become ‘*stuck in habits*’ [A6] and followed the protocol to which they are used to, rather than change to new protocols. This was reportedly due to the fact that they had spent a long time finding what worked for them in their setting and so were concerned that new guidelines would add to their already overburdened workload. Two health professionals felt that they were too close to retirement to bother changing processes and learning new protocols would be a lot of work for a short time. In comparison, one of the younger health professionals felt she was more open to new training and changes to hospital procedures as she had just come from a training environment and could see a better long term opportunity to improve her professional position.

“Breaking and changing peoples’ habits, taking people out of their comfort zone is difficult. It requires a slow, meticulous process in developing things, just a way of documenting glucose, it’s a simple things that’s taken about nine months to get it ordained by everyone, So unfortunately the cogs of the wheel in this huge bureaucracy move very slowly.” [A6]

One important, but particularly difficult and time-consuming, strategy that all of the of health professionals noted would help speed up the implementation of improvement strategies is

that of prioritising staff buy-in. Providers suggested this would call for all staff to be consulted and engaged with plans for change before they take place. They felt that this would not only help to identify the potential problems of the proposed programme before implementation but also encourage staff to understand and proactively engage in implementing new interventions.

“I think sometimes the resistance is always from staff initially. Is it added work for us? How are we going to fit this into an already tight schedule? And usually the resistance decreases when you can see the impact.” [A1]

It is important to note however that the key concern is *how* staff are engaged rather than just engaging widely. For example, five health professionals felt that workshops and personal engagement were more useful than receiving a long text about changes. This is because workshops served as a fresh break from normal routine, where staff could relax, learn, and be treated to a nice lunch, and also served as a space for staff to ask questions and receive feedback. As a result, staff are more likely retain information than just from reading an impersonal text. In addition, all providers noted that staff need to feel that they are being included in changes and that their opinion is actually truly wanted and valued – allowing staff to take active ownership over new interventions.

“When you having the meetings with the people who are doing the work it will be much better. And they will see that the people that’s doing the work, like us here, we will come up with the right solutions because we deal with it on a daily basis and not management upstairs.” [B1]

All the health professionals agreed that staff, of all ages, often withdrew resistance to new programmes once they understood the bigger aim of the program as they particularly needed to see in what ways it would benefit them and patients before committing to new protocol. Insubstantial engagement on the other hand could lead to continued resistance to new hospital processes

“Communication is good. But sometimes communication is very bad amongst staff. With the doctors included. And the higher authority there. They just come on us and dump things on us ‘dwah’. Like we are robots. We are not robots, we are also human beings but to them we are just a workforce, they must call us the workforce ... Not to say that we don’t have a say but when it comes to us its already decided ... [the relationship between nurses and doctors is] very professional. They just give orders, we’re the followers ... some of them don’t even greet you, they just greet you if they want something.” [B3]

“The resistance came from the staff, top management is trying to implement it and staff is giving them problems. But then I myself was not happy with it because I had to do things another way...we not always happy with changes, even if the changes are for the good, we are not happy...when we started I didn’t want to be involved, and now fortunately I am involved in it but I thought it was bad in the beginning because I thought I’m over 50 why must I still learn these new things...why don’t they teach the young ones this? But it’s working, because of that the amount of patients at [the hospital] has decreased but we didn’t see the bigger picture.” [B1]

Notwithstanding communication challenges, several factors were identified by health professionals as motivating them to engage actively with patients. Three providers had family members who have diabetes or have diabetes themselves and so felt they could better understand a patient's situation and experienced a great urge to help. Five of the health providers mentioned that they enjoyed being able to learn new skills such as different disease care, healthy lifestyle habits or counselling skills but, considering the extra time needed to do these things on top of an already over-burdened workload, were additionally motivated to learn when it might lead to promotion, increased pay or meaningful recognition for the extra qualification. Two health professionals emphasised that when they were trusted by health care leaders to make autonomous decisions about care in real-time they gained a sense of confidence and motivation that they are good at their jobs and are able to improve their patients' outcomes.

"So I decided myself, the doctor was not there, that they need to write to the social workers, I decided that the patient must be seen by the social worker. When Prof came Monday then I was handing over to Prof and saying there was this patient Friday, I did this and that. She really appreciated that. So they don't have that, they trust." [B5]

Five health professionals also mentioned that staff are more committed to their work if they are seen as human beings with personal needs. Examples of motivating experiences that they had in this regard included receiving public praise for work done well or, for one health provider, taking time to celebrate her birthday and reminding her that she is special and valued in the health team. Two other health professionals mentioned that many staff feel resentful towards their health organisation when they are not given decent leave to enjoy holidays with their loved ones.

Discussion

This study aimed to explore what factors may influence the implementation and effectiveness of interventions to support patient empowerment for diabetes care in a South African tertiary hospital setting. It found that wider issues of patient background and health system context throw up barriers to implementing such interventions and to the potential for these interventions to enhance patients' ability to care actively for their chronic disease. The range of factors identified in the study is summarised and synthesised by adapting Bravo et al., 2015 model of patient empowerment, as seen in Figure 1. The Figure largely reflects the original model proposed by these authors as this study found similar patient empowerment indicators and outcomes [16]. However, it adds detail to the model in the form of a fuller analysis of the moderators that affect health interventions and the level of patient empowerment within the inpatient setting – as highlighted in red.

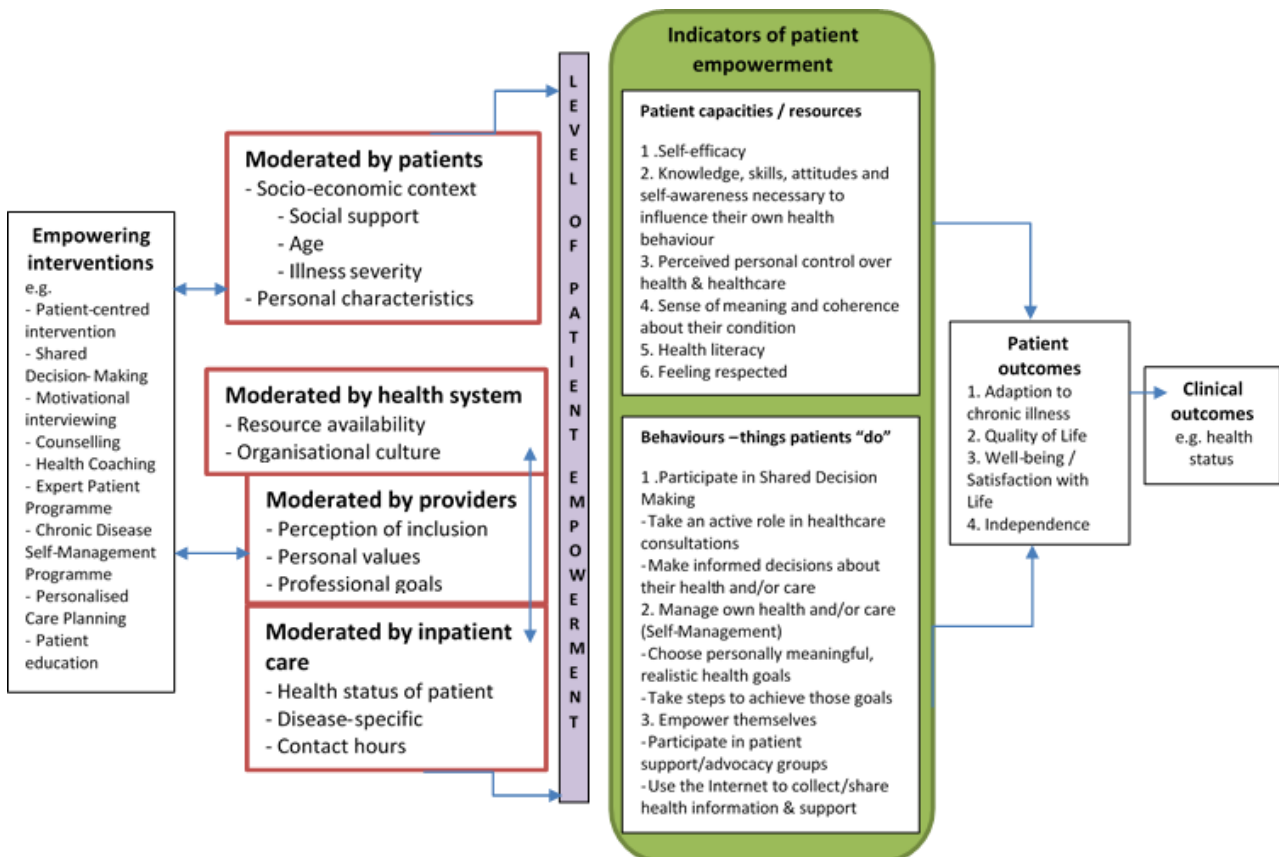


Figure 1 Factors affecting patient empowerment interventions. Adapted from Bravo et al., 2015

Patient empowerment levels moderated by patient factors

As illustrated in Figure 1, the study found that the socio-economic context of patients greatly affects a person's ability to engage with their health care over the long term, as also noted in wider literature. Specifically, chronic care patients that come from a low socio-economic background often experience barriers to accessing quality health care and do not have the social and financial support to encourage long term lifestyle changes [17,18]. In the study reported here, young and dependent groups within a low SES setting in particular were found to be misinformed about chronic diseases and engage in activities that do not support long term health care. Comparatively, patients with greater resilience, support, and independence are better able to navigate the barriers to caring for their chronic disease [16, 19].

There are multiple reasons that could explain why this would be the case in South Africa. For one, nearly one third of the South African population is unemployed [20]. Unemployment has been widely noted around the world and in South Africa to increase levels of boredom as well as decrease a person's confidence in their abilities and lead to high levels of uncertainty and feelings of isolation [21]. Youth may then cope with these negative feelings by engaging in risky and unhealthy behaviours or by reacting aggressively to health professionals' advice. Another contributing factor could be the trend towards urbanisation. In South Africa, the highest proportion of the NCD burden occurs in poor urban areas [3]. Urbanisation often leads to increased intake of cheap, processed foods and to sedentary lifestyles that contribute to the development of NCDs and make it difficult to follow lifestyles that support healthy living [22]. These reasons contribute to the difficulty in accessing appropriate health care and maintaining care for one's chronic disease over a long time.

Patient empowerment levels moderated by health system, provider, and inpatient factors

Factors within a health system can be understood within a hardware and software framework [23-25]. A system's hardware comprises tangible resources and structures such as finances, infrastructure, medicine and technology availability, and staff availability. As seen in Figure 1, this resource availability affects the success of empowerment-focused interventions as resource constraints impede providers' abilities to motivate patients to care for their chronic illness as they do not have the finances, resources, and training necessary to implement effective patient-centred strategies [26]. Resource availability continues to be a major barrier in LMICs where funding for healthcare is largely allocated towards infectious diseases such as HIV and TB and little is directly earmarked for NCDs [2]. In addition, there is a lack of trained health workers and low retention of the health workforce. In South Africa, specifically, experience shows that there are high levels of inappropriate referrals and delayed diagnosis and care for those with chronic illnesses due to unavailability or inefficiency of services and staff [27].

A system's software on the other hand contains tangible elements such as information use, skills development, decision-making processes, and planning and budgeting processes, as well as intangible elements such as values, power, trust, and norms that govern actions between the people who work within the system, including providers and patients. Figure 1 illustrates the findings in the study that a system's organisational culture, including leadership patterns and communication style, affects the success of empowerment-focused interventions. For example, South Africa has a history of centralised and hierarchical decision-making within health care undermining providers' and communities' engagement in service delivery decision-making [3]. This has resulted in the development of many inappropriate policies that are not well implemented on the ground level, slowing down potential service delivery improvements [28].

Leadership and decision-making strategies that do not adequately consider the needs and capabilities of frontline workers can also result in dissatisfaction and lack of commitment from providers, who in turn moderate the effectiveness of empowerment-focused interventions [29]. If health providers perceive that they are not being adequately trusted, appreciated, and included in health care decisions then they can often be demotivated to provide quality services and implement new interventions [26]. Furthermore, health professionals' own personal values and professional goals can affect their motivation to implement new interventions [26,29]. This includes whether the provider feels competent to provide the interventions, whether the provider sees that they are able to attain the professional opportunities that they would like, as well as the openness and willingness of the provider to change, which can itself be mediated by factors such as level of training and age of provider.

As Figure 1 highlights, this study also specifically considered the role that inpatient care plays in patient engagement. The study's finding that patients may be too sick to engage in and retain information on long term lifestyle change education within an inpatient setting is supported by wider experience [30]. In addition, the disease-based structure of the hospital setting can result in limited holistic care for patients and increased need for re-admission [31]. Within the inpatient setting, the shortage of staff and limited patient beds means health providers are also under pressure to treat and discharge patients as quickly as possible leading to increasingly controlling and rushed patient-provider interactions [32]. However, hospitalisation is a prolonged point of contact between patients and health professionals that could prove useful for patient-centred interventions [33].

The implications of study findings

Health interventions that aim to engage patients in long term care should consider relevant patient and health system factors that moderate levels of patient empowerment. For example, to better support patients and equip them post-discharge counselling sessions could be provided during inpatient care in order to increase a person's internal locus of control and confidence in their abilities to take control of situations and empower them to take active, independent steps to care for their health, despite their surroundings [34]. Interventions would also need to provide practical resources that incorporate patient context such as information on where to access healthy food alternatives at affordable prices and how to incorporate exercise into a busy schedule in ways that emphasise the values and goals of patients [35]. Patients should also be introduced to accessible and positive peer support structures that can provide continuous information and encouragement [9]. These can include health clubs, social workers, community leaders, religious leaders and other welfare groups that can support patients in both their health and non-health goals.

Other strategies that hospitals can implement in order to provide holistic and patient-centred care include holding regular disease 'expos' within the hospital in order to bring together staff and patients from different wards in a relaxed and more informal way to learn about the similarities of causes and care between diseases [36]. Hospital staff should also set up strong relationships with possible discharge facilities in order to streamline patient discharge. Hospital leaders and clinicians can also serve as advocates for other important provincial and national public health interventions that support long term patient empowerment [2,3].

To enable these activities, interventions should be based on better understanding patient needs, and the specific needs of young, newly diagnosed patients, in order to guide empowerment building activities and comprehend the role that inpatient care can play. In addition, priority should be given to strategies that reduce the workload of health professionals in order to prevent staff

burnout and demotivation and in order for providers to have more time to engage with patients and implement empowerment strategies [26,32]. For example, this can be achieved in part by simplifying and reducing administrative tasks or engaging in clear task-shifting strategies [37]. Similarly, staff can develop a system for identifying which patients are well enough to engage in their care and are able to administer their own medication during their hospital stay in order to empower these patients and alleviate some of the provider's workload [30,33]. Additionally, better communication and leadership practices amongst staff will help to motivate health professionals to engage in patient-centred interventions. This includes mutual constructive engagement that fosters trust as well as ensures everyone understands the intervention vision, feels included in intervention development, and can see the improvements that are a result of their work [9,26,38,39].

Limitations

There are various limitations to this study. For one, many inpatients were too sick and so unwilling to be interviewed. This means that those who were interviewed had a certain level of health and enthusiasm to participate that is not indicative of the entire inpatient population; making it difficult to generalise factors found to affect inpatient engagement in care. Similarly, four of the seven patients interviewed had only recently been diagnosed with diabetes and all patients had very recently been in inpatient care or were currently in inpatient care. This makes it difficult to gauge from the patients' perspective how they felt that inpatient care helped their feelings of empowerment in the long term. Rather, long term inpatient care effects on patients' feelings and behaviours were largely understood through the experiences of the healthcare providers and not only from the patients interviewed.

Despite these constraints, the study participants offered a wide range of experiences in diabetes inpatient care and the findings offer ideas that can be further considered in the longer term intervention assessment, as well as in other healthcare settings.

Conclusion

In conclusion, there are multiple barriers and facilitators within the patient and health system context that affect the ability of a patient to engage in long term care for a chronic disease and the ability of health facilities to implement patient empowerment interventions. However, knowledge of these barriers and facilitators is important in developing strategies to improve patient empowerment. Considering the prolonged contact between patient and health professionals within the inpatient setting, hospitals that consider these factors provide a valuable opportunity for these strategies.

References

1. Hofman K. Non-communicable diseases in South Africa: A challenge to economic development. *South African Medical Journal*. 2014; doi:10.7196/SAMJ.8727.
2. Samb B, Desai N, Nishtar S, Mendis S, Bekedam H, Wright A, et al. Prevention and management of chronic disease: A litmus test for health-systems strengthening in low-income and middle-income countries. *The Lancet*. 2010; doi:10.1016/S0140-6736(10)61353-0.
3. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D. The burden of non-communicable diseases in South Africa. *The Lancet*. 2009; doi:10.1016/S0140-6736(09)61087-4.
4. Alwan A, MacLean DR, Riley LM, d'Espaignet ET, Mathers CD, Stevens GA, et al. Monitoring and surveillance of chronic non-communicable diseases: progress and capacity in high-burden countries. *The Lancet*. 2010; doi: 10.1016/S0140-6736(10)61853-3.
5. Dalal S, Beunza JJ, Volmink J, Adebamowo C, Bajunirwe F, Njelekela M, et al. Non-communicable diseases in sub-Saharan Africa: what we know now. *International Journal of Epidemiology*. 2011; doi: 10.1093/ije/dyr050.
6. Anderson RM, Funnell MM. Patient empowerment: Myths and misconceptions. *Patient Education and Counseling*. 2010; doi:10.1016/j.pec.2009.07.025.
7. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*. 2006; doi:10.1016/j.pec.2006.09.008
8. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA*. 2002; doi:10.1001/jama.288.19.2469.
9. Davy C, Bleasel J, Liu H, Tchan M, Ponniah S, Brown A. Factors influencing the implementation of chronic care models: A systematic literature review. *BMC Family Practice*. 2015; doi:10.1186/s12875-015-0319-5.
10. Epping-Jordan J, Pruitt S, Bengoa R, Wagner E. Improving the quality of health care for chronic conditions. *Quality & Safety in Health Care*. 2004; doi:10.1136/qshc.2004.010744.
11. Norris SL, Engelgau MM, Venkat Narayan KM. Effectiveness of self-management training in type 2 diabetes. *Diabetes Care*. 2001;24:561-587.
12. Gilson L. Doing health policy and systems research: Key steps in the process. In: *Health policy and systems research: A methodology reader*. World Health Organisation. 2012. http://www.who.int/alliance-hpsr/alliancehpsr_reader.pdf. Accessed 09 Nov 2016.
13. Sobh R, Perry C. Research design and data analysis in realism research. *European Journal of Marketing*. 2006; doi:10.1108/03090560610702777.
14. Fletcher AJ. Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology*. 2017; doi:10.1080/13645579.2016.1144401.
15. Westthorp G. Realist impact evaluation: An introduction. *Methods Lab*. 2014. <https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9138.pdf>. Accessed 15 Mar 2017.
16. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M, et al. Conceptualising patient empowerment: A mixed methods study. *BMC Health Services Research*. 2015; doi:10.1186/s12913-015-0907-z.
17. Kardas P, Lewek P, Matyjaszczyk M. Determinants of patient adherence: A review of systematic reviews. *Frontiers in Pharmacology*. 2013; doi:10.3389/fphar.2013.00091.
18. Mackian S, Bedri N, Lovel H. Up the garden path and over the edge: Where might health-seeking behaviour take us? *Health Policy and Planning*. 2004; doi:10.1093/heapol/czh017.
19. Yi JP, Vitaliano PP, Smith RE, Yi JC, Weinger K. The role of resilience on psychological adjustment and physical health in patients with diabetes. *British Journal of Health Psychology*. 2008; doi:10.1348/135910707X186994.

20. Moya S. South Africa unemployment rate. 2018. <https://tradingeconomics.com/south-africa/unemployment-rate>. Accessed 08 Jun 2018.
21. De Witte H, Rothmann S, Jackson LTB. The psychological consequences of unemployment in South Africa. *South African Journal of Economic and Management Sciences*. 2012; doi:10.4102/sajems.v15i3.153.
22. Kruger HS, Puoane T, Senekal M, van der Merwe T. Obesity in South Africa: challenges for government and health professionals. *Public Health Nutrition*. 2005; doi:10.1079/PHN2005785.
23. CHEPSAA. Recognising agents in health systems ... and complexity. 2015. https://www.slideshare.net/hpsa_africa/recognising-agents-in-health-systemsand-complexity. Accessed 01 May 2018.
24. Sheik K, Gilson L, Agyepong IA, Hanson K, Ssengooba F, Bennett S. Building the field of health policy and systems research: Framing the questions. *PLoS Medicine*. 2011; doi: 10.1371/journal.pmed.1001073.
25. Ellokori S, Olckers P, Gilson L, Lehmann U. Crises, Routines and Innovations – the complexities and possibilities of sub-district management. In: Padarath A, English E, editors. *South African Health Review*. Durban: Health Systems Trust; 2013. p. 161-173.
26. Willis-Shattuck M, Bidwell P, Thomas S, Wyness L, Blaauw D, Ditlopo P. Motivation and retention of health workers in developing countries: a systematic review. *BMC Health Services Research*. 2008; doi:10.1186/1472-6963-8-247.
27. Goudge J, Gilson L, Russell S, Gumede T, Mills A. Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 2009; doi:10.1186/1472-6963-9-75.
28. Mayosi BM, Lawn JE, van Niekerk A, Bradshaw D, Abdool Karim SS, Coovadia HM, et al. Health in South Africa: Changes and challenges since 2009. *The Lancet*. 2012; doi:10.1016/S0140-6736(12)61814-5.
29. Aarons GA. Measuring provider attitudes toward evidence-based practice: consideration of organizational context and individual differences. *Child and Adolescent Psychiatric Clinics of North America*. 2005; doi:10.1016/j.chc.2004.04.008.
30. Shah AD, Rushakoff RJ. Patient self-management of diabetes care in the inpatient setting: Con. *Journal of Diabetes Science and Technology*. 2015; doi:10.1177/1932296815586581.
31. Williams MV. A requirement to reduce readmissions: take care of the patient, not just the disease. *JAMA*. 2013;309;394-6.
32. Pelzang R. Time to learn: understanding patient-centred care. *British Journal of Nursing*. 2010; doi:10.12968/bjon.2010.19.14.49050.
33. Maybrey ME, Setji TL. Patient self-management of diabetes care in the inpatient setting: Pro. *Journal of Diabetes Science and Technology*. 2015; doi:10.1177/1932296815590827.
34. Náfrádi L, Nakamoto K, Schulz PJ. Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. *PLoS ONE*. 2017, doi:10.1371/journal.pone.0186458.
35. Masupe TK, Ndayi K, Tsolekile L, Delobelle P, Puoane T. Redefining diabetes and the concept of self-management from a patient's perspective: Implications for disease risk factor management. *Health Education Research*. 2018; doi:10.1093/her/cyx077.
36. Costers M, Viseur N, Catry B, Simon A. Four multifaceted countrywide campaigns to promote hand hygiene in Belgian hospitals between 2005 and 2011: impact on compliance to hand hygiene. *Euro Surveillance*. 2012;17:18.
37. World Health Organisation. Task shifting: global recommendations and guidelines. Geneva: WHO Press; 2007.
38. CHEPSAA. Leadership and change in health systems. 2015. https://www.slideshare.net/hpsa_africa/leadership-and-change-in-health-systems. Accessed 12 June 2018.
39. Blaauw D, Gilson L, Penn-Kekana L, Scheider H. Organisational relationships and the 'software' of health sector reform. 2003.

https://www.researchgate.net/publication/250845181_Organisational_Relationships_and_the_Software_of_Health_Sector_Reform. Accessed 03 Jun 2018.

APPENDICES

Appendix A: Invitation to participate in the research

INFORMATION SHEET: KEY INFORMANT INTERVIEW

Factors that influence patient empowerment in inpatient chronic care: An evaluation of a diabetes care intervention in South Africa

We are conducting an evaluation study that looks to better understand the role of patient empowerment in inpatient hospital care. The primary research question is:

What factors of inpatient diabetes care influence patient empowerment in a South African hospital?

This research will help influence future hospital interventions that focus on supporting and empowering patients in chronic care.

Study procedures:

- A series of interviews with key stakeholders who have insight into patient experiences of chronic care
- In-depth research of current literature in order to better understand and support the perspectives gathered through the interviews

Your participation:

You have been asked to participate in this study because you have been identified as a key stakeholder able to provide valuable information on inpatient chronic care. This may include knowledge about changing health care practices for diabetes, patient and staff motivation, and the needs of different stakeholders.

Empowerment – the theme of this research – refers to feelings of motivation and ability to take control and self-manage one's care inside and outside of the hospital setting. This study will be exploring these thoughts and feelings using a semi-structured interview method. There are therefore no right or wrong answers to the questions that we will ask as all experiences are valid.

What are the processes and procedures during and after the interviews?

- Participants must be over the age of 18 and have knowledge of the diabetes inpatient care at the hospital under review.
- Participants should have English as a first or second language. Interviews will be conducted in English but an interpreter will be provided if you request.
- We will first go through an informed consent form that outlines your role and the researcher's role in the research. If you choose to participate then this will be signed.
- We expect that completing the interview will take around 60 minutes.
- The interviewer will guide the interview in a semi-structured way, asking you questions about your experiences of inpatient care.

- The interviews will take place in a venue of your choice, in a quiet location where no interruptions are likely to occur.
- Should you agree, the interview will be audio recorded to ensure accuracy of later transcriptions.
- No identifying information will be transcribed. A code, known only by the research coordinator, will be created that links you to your interview.
- You may contact the researcher at any time before and after the interview to clarify information.
- All documents and recordings will be kept in files on a computer that are password protected. Interview sheets and documents will be kept in files that will be stored safely in a locked cupboard.
- If you would like to provide contact information, the completed research report will be sent to you.

Your right to participate, not participate, or withdraw from this study?

- Your participation in this study is entirely voluntary.
- Complete answers are most helpful for the research, but if you decide to participate, you may refuse to answer any question and you are free to stop at any time.
- Your participation choice will not in any way affect your relationship with your healthcare setting.

What are the expected risks or benefits to you or to others for participating in this research study?

- This is considered a minimal risk study. All efforts will be made by the researchers to minimise any risks.
- You will not be paid for participating in this study and there will be no direct benefits to you as a participant.
- The results from this research will be used to better inform chronic care changes made in South African healthcare settings.

Who is carrying out this study?

This research is being conducted by researchers at the School of Public Health and Family Medicine division at the University of Cape Town as part of a Master's program. You may contact either the Primary Investigator (Gilson), or the research coordinator (Abrahams) with any further queries.

Prof Lucy Gilson (PI)

Head of Health Policy and Systems Division

University of Cape Town, School of Public Health and Family Medicine, Anzio Road, Observatory, Cape Town 7925, South Africa

Phone: +27 (0)21 406 6272

Email: lucy.gilson@uct.ac.za

Nina Abrahams (Research coordinator)

Public Health Master's student

University of Cape Town, School of Public Health and Family Medicine, Anzio Road, Observatory, Cape Town 7925, South Africa

Phone: +27 (0)79 909 9399

Email: ntabrahams@gmail.com

Ethical clearance?

This study has been reviewed and approved by the University of Cape Town Health Sciences Faculty Human Research Ethics Committee. The UCT HREC can be contacted directly to confirm this clearance, or should you have any further questions about this study and need independent and objective information:

Human Research Ethics Committee of the Health Sciences Faculty

University of Cape Town, The Faculty of Health Sciences, Human Research Ethics Committee

E 52, Room 24, Old Main Building, Groote Schuur Hospital, Observatory, 7925, South Africa

Telephone: +27 21 406 6338

Appendix B: Interview schedule for first phase

Intervention developers

- Tell me about your background
 - What discipline are you from and currently in?
 - How long you have been working in chronic and specifically diabetes care?
- What is your role in the intervention?
- Why have you created this intervention?
 - What are you hoping it will achieve?
- In your experience, how would you describe an empowered patient?
 - How would you describe a disempowered patient?
- What factors influence patient empowerment?
 - Think about patient characteristics such as socio-economic status
 - Think about staff characteristics
 - Think about hospital characteristics
 - Think about the intervention characteristics

Health professionals

- Tell me about your background
 - What discipline are you from and currently in?
 - How long you have been working in chronic and specifically diabetes care?
- What is your role in the intervention?
- What factors help you implement the intervention?
 - What factors hinder implementation of the intervention?
- In your experience, how would you describe an empowered patient?
 - How would you describe a disempowered patient?

- What factors influence patient empowerment?
 - Think about patient characteristics such as socio-economic status
 - Think about staff characteristics
 - Think about hospital characteristics
 - Think about intervention characteristics

Patients

- Tell me more about yourself
 - Your age, family, education, employment, where you live
- Tell me more about your diabetes diagnosis and other possible diagnoses
- What do you think about the care received for your diabetes in the hospital? Talk me through your experience.
 - Compare it to other types of diabetes care you have received such as in other hospitals or other levels of healthcare.
- How would you describe an empowered patient?
 - Think about feelings like being in control, feeling knowledgeable, feeling confident, being able to administer your own medication
- Do you, or have you ever, felt empowered about self-managing your diabetes care outside of the hospital?
 - Think about your own definition of empowerment
 - What made you feel empowered or disempowered?
- How have different contexts influenced your diabetes care experience? How have these contexts influenced your feelings of empowerment or disempowerment? Think about:
 - Staff characteristics
 - Hospital characteristics
 - Home characteristics
- How much are you included by hospital staff in developing your hospital treatment plan?
 - For example, do you always understand what is expected of you? Do you or do health professionals administer your medication?

- Would you like to be more or less included by health professionals? Why?
- What types of information or skills have helped you feel that you can effectively self-manage your health?
 - What types of information or skills would you like in order to improve your diabetes care?
- Have you been able to use your skills to help others in a similar situation?

Appendix C: Informed consent

Consent for Participation in Interview Research

University of Cape Town

I volunteer to participate in a research project conducted by Nina Abrahams from the University of Cape Town. I understand that the project is designed to gather information about experiences of empowerment in diabetes hospital care. I am aware that this research has been approved by a registered ethics committee.

Voluntary Participation

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and discontinue participation at any time without penalty. If I decline to participate or withdraw from the study, I will not lose any services from the hospital under review.
2. I understand that most people will find the discussion interesting and thought-provoking. If, however, I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

Study Procedure

3. Participation involves being interviewed by a researcher from the University of Cape Town. The interview will last approximately one hour. Notes will be written during the interview. In addition an audio tape of the interview will be made. I understand that participation in the study includes agreeing to the interview process being voice recorded.

Confidentiality

4. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

5. Health professionals from the hospital and the University of Cape Town will neither be present at the interview nor have access to raw notes or transcripts. This precaution will prevent my individual comments from having any negative repercussions.

Possible Risks/Benefits

6. There are no foreseeable risks involved in participating in this study. Some of the topics discussed may be sensitive or emotional and have an impact on me. In the event of this happening I will be referred to a hospital social worker.

7. While there are no material benefits to participating in this study, I will have a chance to speak about and engage with my experiences. I will also be making a valuable contribution towards research around chronic care in South Africa.

Consent

8. I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction and I voluntarily agree to participate in this study.

9. I have been given a copy of this consent form.

My Signature

My Printed Name

Date

Signature of the Investigator

Any questions, queries and concerns about the study can be directed to:

Nina Abrahams (Investigator) ntabrahams@gmail.com 079 909 9399

Prof Lucy Gilson (Supervisor) lucy.gilson@uct.ac.za

The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any ethical concerns or questions about your rights or welfare as a participant on this research study.

Appendix D: Ethics Clearance



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6492
Email: sumayyah.aredien@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/forms

26 September 2017

HREC REF:484/2017

Prof L Gilson
Division of Public Health & Family Medicine
Falmouth Building-FHS

Dear Prof Gilson

PROJECT TITLE: FACTORS THAT INFLUENCE PATIENT EMPOWERMENT IN INPATIENT CHRONIC CARE: AN EVALUATION OF A DIABETES CARE INTERVENTION IN SOUTH AFRICA (MASTERS CANDIDATE - MS N ABRAHAMS)

Thank you for your response letter dated 19 September 2017, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 September 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: N Abrahams will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 484/2017

Appendix E: Journal Style Guide

Aims and scope

BMC Health Services Research is an open access, peer-reviewed journal that considers articles on all aspects of health services research, including delivery of care, management of health services, assessment of healthcare needs, measurement of outcomes, allocation of healthcare resources, evaluation of different health markets and health services organizations, international comparative analysis of health systems, health economics and the impact of health policies and regulations.

Article-processing charges

Open access publishing is not without costs. *BMC Health Services Research* therefore levies an article-processing charge of £1370/\$2145/€1745 for each article accepted for publication. If the corresponding author's institution participates in our open access membership program, some or all of the publication cost may be covered (more details available on the [membership page](#)). We routinely waive charges for authors from [low-income countries](#). For other countries, article-processing charge waivers or discounts are granted on a case-by-case basis to authors with insufficient funds. Authors can request a waiver or discount during the submission process. For further details, see our [article-processing charge page](#).

BioMed Central provides a free open access funding support service to help authors discover and apply for article processing charge funding. Visit our [OA funding and policy support page](#) to view our list of research funders and institutions that provide funding for APCs, and to learn more about our email support service.

Research article

Criteria

Research articles should report on original primary research, but may report on systematic reviews of published research provided they adhere to the appropriate reporting guidelines which are detailed in our [editorial policies](#). Please note that non-commissioned pooled analyses of selected published research will not be considered.

BMC Health Services Research strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible. Please see Springer Nature's [information on recommended repositories](#). Where a widely established research community expectation for data archiving in public repositories exists, submission to a community-endorsed, public repository is mandatory. A list of data where deposition is required, with the appropriate repositories, can be found on the [Editorial Policies Page](#).

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:

- "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
 - or for non-clinical or non-research studies a description of what the article reports
- list the full names, institutional addresses and email addresses for all authors
 - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the [CONSORT](#) extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our [editorial policies](#) for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and material
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval.

See our [editorial policies](#) for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our [consent form](#) if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our [editorial policies](#) for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available [here](#).

BioMed Central also requires that authors cite any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. <http://dx.doi.org/10.6084/m9.figshare.853801>

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].^[Reference number]

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our [editorial policies](#) for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each author's competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding

All sources of funding for the research reported should be declared. The role of the funding body in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript should be declared.

Authors' contributions

The individual contributions of authors to the manuscript should be specified in this section. Guidance and criteria for authorship can be found in our [editorial policies](#).

Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

See our [editorial policies](#) for a full explanation of acknowledgements and authorship criteria.

If you do not have anyone to acknowledge, please write "Not applicable" in this section.

Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the submission system and also include collaborating author names as the last paragraph of the "Acknowledgements" section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or country information for each author if you wish, but this should be consistent across all authors.

Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

Authors' information

This section is optional.

You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Endnotes

Endnotes should be designated within the text using a superscript lowercase letter and all notes (along with their corresponding letter) should be included in the Endnotes section. Please format this section in a paragraph rather than a list.

References

All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. The reference numbers must be finalized and the reference list fully formatted before submission.

Examples of the BioMed Central reference style are shown below. Please ensure that the reference style is followed precisely.

See our editorial policies for author guidance on good citation practice.

Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format: The Mouse Tumor Biology Database.

<http://tumor.informatics.jax.org/mtbwi/index.do>. Accessed 20 May 2013. If an author or group of authors can clearly be associated with a web link (e.g. for blogs) they should be included in the reference.

Example reference style:

Article within a journal

Smith JJ. The world of science. *Am J Sci*. 1999;36:234-5.

Article within a journal (no page numbers)

Rohrmann S, Overvad K, Bueno-de-Mesquita HB, Jakobsen MU, Egeberg R, Tjønneland A, et al. Meat consumption and mortality - results from the European Prospective Investigation into Cancer and Nutrition. *BMC Med*. 2013;11:63.

Article within a journal by DOI

Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. *Dig J Mol Med*. 2000; doi:10.1007/s801090000086.

Article within a journal supplement

Frumin AM, Nussbaum J, Esposito M. Functional asplenia: demonstration of splenic activity by bone marrow scan. *Blood* 1979;59 Suppl 1:26-32.

Book chapter, or an article within a book

Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. *International review of cytology*. London: Academic; 1980. p. 251-306.

OnlineFirst chapter in a series (without a volume designation but with a DOI)

Saito Y, Hyuga H. Rate equation approaches to amplification of enantiomeric excess and chiral symmetry breaking. *Top Curr Chem*. 2007. doi:10.1007/128_2006_108.

Complete book, authored

Blenkinsopp A, Paxton P. *Symptoms in the pharmacy: a guide to the management of common illness*. 3rd ed. Oxford: Blackwell Science; 1998.

Online document

Doe J. Title of subordinate document. In: *The dictionary of substances and their effects*. Royal Society of Chemistry. 1999. <http://www.rsc.org/dose/title of subordinate document>. Accessed 15 Jan 1999.

Online database

Healthwise Knowledgebase. US Pharmacopeia, Rockville. 1998. <http://www.healthwise.org>. Accessed 21 Sept 1998.

Supplementary material/private homepage

Doe J. Title of supplementary material. 2000. <http://www.privatehomepage.com>. Accessed 22 Feb 2000.

University site

Doe, J: Title of preprint. <http://www.uni-heidelberg.de/mydata.html> (1999). Accessed 25 Dec 1999.

FTP site

Doe, J: Trivial HTTP, RFC2169. <ftp://ftp.isi.edu/in-notes/rfc2169.txt> (1999). Accessed 12 Nov 1999.

Organization site

ISSN International Centre: The ISSN register. <http://www.issn.org> (2006). Accessed 20 Feb 2007.

Dataset with persistent identifier

Zheng L-Y, Guo X-S, He B, Sun L-J, Peng Y, Dong S-S, et al. Genome data from sweet and grain sorghum (*Sorghum bicolor*). GigaScience Database. 2011. <http://dx.doi.org/10.5524/100012>.

Figures, tables additional files

See [General formatting guidelines](#) for information on how to format figures, tables and additional files.

Preparing your manuscript

This section provides general style and formatting information only. Formatting guidelines for specific article types can be found below.

- [Research article](#)
- [Technical advance article](#)
- [Database article](#)
- [Software article](#)
- [Debate](#)
- [Case report](#)
- [Study protocol](#)

General formatting guidelines

- [Preparing main manuscript text](#)
- [Preparing illustrations and figures](#)
- [Preparing tables](#)
- [Preparing additional files](#)

Preparing main manuscript text

Quick points:

- Use double line spacing
- Include line and page numbering
- Use SI units: Please ensure that all special characters used are embedded in the text, otherwise they will be lost during conversion to PDF
- Do not use page breaks in your manuscript

File formats

The following word processor file formats are acceptable for the main manuscript document:

- Microsoft word (DOC, DOCX)

- Rich text format (RTF)
- TeX/LaTeX (use BioMed Central's TeX template)

Please note: editable files are required for processing in production. If your manuscript contains any non-editable files (such as PDFs) you will be required to re-submit an editable file when you submit your revised manuscript, or after editorial acceptance in case no revision is necessary.

Note that figures must be submitted as separate image files, not as part of the submitted manuscript file. For more information, see [Preparing figures](#) below.

Additional information for TeX/LaTeX users

Please use BioMed Central's TeX template and BibTeX stylefile if you use TeX format. Submit your references using either a bib or bbl file. When submitting TeX submissions, please submit both your TeX file and your bib/bbl file as manuscript files. Please also convert your TeX file into a PDF (please do not use a DIV file) and submit this PDF as a supplementary file with the name 'Reference PDF'. This PDF will be used by our production team as a reference point to check the layout of the article as the author intended. Please also note that all figures must be coded at the end of the TeX file and not inline.

The Editorial Manager system checks for any errors in the Tex files. If an error is present then the system PDF will display LaTeX code and highlight and explain the error in a section beginning with an exclamation mark (!).

All relevant editable source files must be uploaded during the submission process. Failing to submit these source files will cause unnecessary delays in the production process.

TeX templates
BioMedCentral_article (ZIP format) - preferred template
Springer_article svjour3 (ZIP format)
birkjour (Birkhäuser, ZIP format)
article (part of the standard TeX distribution)
amsart (part of the standard TeX distribution)

Style and language

For editors and reviewers to accurately assess the work presented in your manuscript you need to ensure the English language is of sufficient quality to be understood. If you need help with writing in English you should consider:

- Visiting the [English language tutorial](#) which covers the common mistakes when writing in English.
- Asking a colleague who is a native English speaker to review your manuscript for clarity.
- Using a professional language editing service where editors will improve the English to ensure that your meaning is clear and identify problems that require your review. Two such services are provided by our affiliates [Nature Research Editing Service](#) and [American Journal Experts](#). BMC authors are entitled to a 10% discount on their first submission to either of these services. To claim 10% off English editing from Nature Research Editing Service, click [here](#). To claim 10% off American Journal Experts, click [here](#).

Please note that the use of a language editing service is not a requirement for publication in the journal and does not imply or guarantee that the article will be selected for peer review or accepted.

Data and materials

For all journals, BioMed Central strongly encourages all datasets on which the conclusions of the manuscript rely to be either deposited in publicly available repositories (where available and appropriate) or presented in the main paper or additional supporting files, in machine-readable format (such as spread sheets rather than PDFs) whenever possible. Please see the list of [recommended repositories](#) in our editorial policies. For some journals, deposition of the data on which the conclusions of the manuscript rely is an absolute requirement. Please check the Instructions for Authors for the relevant journal and article type for journal specific policies.

For all manuscripts, information about data availability should be detailed in an 'Availability of data and materials' section. For more information on the content of this section, please see the Declarations section of the relevant journal's Instruction for Authors. For more information on BioMed Centrals policies on data availability, please see our [\[editorial policies\]](#).

Formatting the 'Availability of data and materials' section of your manuscript

The following format for the 'Availability of data and materials' section of your manuscript should be used:

"The dataset(s) supporting the conclusions of this article is(are) available in the [repository name] repository, [unique persistent identifier and hyperlink to dataset(s) in http:// format]."

The following format is required when data are included as additional files:

"The dataset(s) supporting the conclusions of this article is(are) included within the article (and its additional file(s))."

BioMed Central endorses the Force 11 Data Citation Principles and requires that all publicly available datasets be fully referenced in the reference list with an accession number or unique identifier such as a DOI.

For databases, this section should state the web/ftp address at which the database is available and any restrictions to its use by non-academics.

For software, this section should include:

- Project name: e.g. My bioinformatics project
- Project home page: e.g. <http://sourceforge.net/projects/mged>
- Archived version: DOI or unique identifier of archived software or code in repository (e.g. enodo)
- Operating system(s): e.g. Platform independent
- Programming language: e.g. Java
- Other requirements: e.g. Java 1.3.1 or higher, Tomcat 4.0 or higher
- License: e.g. GNU GPL, FreeBSD etc.
- Any restrictions to use by non-academics: e.g. licence needed

Information on available repositories for other types of scientific data, including clinical data, can be found in our [editorial policies](#).

References

See our [editorial policies](#) for author guidance on good citation practice.

All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. The reference numbers must be finalized and the reference list fully formatted before submission. For further information including example references please read our reference preparation guidelines.

What should be cited?

Only articles, clinical trial registration records and abstracts that have been published or are in press, or are available through public e-print/preprint servers, may be cited.

Unpublished abstracts, unpublished data and personal communications should not be included in the reference list, but may be included in the text and referred to as "unpublished observations" or "personal communications" giving the names of the involved researchers. Obtaining permission to quote personal communications and unpublished data from the cited colleagues is the responsibility of the author. Footnotes are not allowed, but endnotes are permitted. Journal abbreviations follow Index Medicus/MEDLINE.

Any in press articles cited within the references and necessary for the reviewers' assessment of the manuscript should be made available if requested by the editorial office.

How to format your references

Examples of the BioMed Central reference style are shown below. Please ensure that the reference style is followed precisely; if the references are not in the correct style, they may need to be retyped and carefully proofread.

Preparing figures

When preparing figures, please follow the formatting instructions below.

- Figures should be provided as separate files, not embedded in the main manuscript file.
- Each figure of a manuscript should be submitted as a single file that fits on a single page in portrait format.
- Tables should NOT be submitted as figures but should be included in the main manuscript file.
- Multi-panel figures (those with parts a, b, c, d etc.) should be submitted as a single composite file that contains all parts of the figure.
- Figures should be numbered in the order they are first mentioned in the text, and uploaded in this order.
- Figures should be uploaded in the correct orientation.
- Figure titles (max 15 words) and legends (max 300 words) should be provided in the main manuscript, not in the graphic file.
- Figure keys should be incorporated into the graphic, not into the legend of the figure.
- Each figure should be closely cropped to minimize the amount of white space surrounding the illustration. Cropping figures improves accuracy when placing the figure in combination with other elements when the accepted manuscript is prepared for publication on our site. For more information on individual figure file formats, see our detailed instructions.
- Individual figure files should not exceed 10 MB. If a suitable format is chosen, this file size is adequate for extremely high quality figures.
- **Please note that it is the responsibility of the author(s) to obtain permission from the copyright holder to reproduce figures (or tables) that have previously been published elsewhere.** In order for all figures to be open access, authors must have permission from the rights holder if they wish to include images that have been published elsewhere in non open access journals. Permission should be indicated in the figure legend, and the original source included in the reference list.

Figure file types

We accept the following file formats for figures:

- EPS (suitable for diagrams and/or images)
- PDF (suitable for diagrams and/or images)
- Microsoft Word (suitable for diagrams and/or images, figures must be a single page)
- PowerPoint (suitable for diagrams and/or images, figures must be a single page)
- TIFF (suitable for images)
- JPEG (suitable for photographic images, less suitable for graphical images)
- PNG (suitable for images)
- BMP (suitable for images)
- CDX (ChemDraw - suitable for molecular structures)

For information and suggestions of suitable file formats for specific figure types, please see our [author academy](#).

Figure size and resolution

Figures are resized during publication of the final full text and PDF versions to conform to the BioMed Central standard dimensions, which are detailed below.

Figures on the web:

- width of 600 pixels (standard), 1200 pixels (high resolution).

Figures in the final PDF version:

- width of 85 mm for half page width figure
- width of 170 mm for full page width figure
- maximum height of 225 mm for figure and legend
- image resolution of approximately 300 dpi (dots per inch) at the final size

Figures should be designed such that all information, including text, is legible at these dimensions. All lines should be wider than 0.25 pt when constrained to standard figure widths. All fonts must be embedded.

Figure file compression

- Vector figures should if possible be submitted as PDF files, which are usually more compact than EPS files.
- TIFF files should be saved with LZW compression, which is lossless (decreases file size without decreasing quality) in order to minimize upload time.
- JPEG files should be saved at maximum quality.
- Conversion of images between file types (especially lossy formats such as JPEG) should be kept to a minimum to avoid degradation of quality.

If you have any questions or are experiencing a problem with figures, please contact the customer service team at info@biomedcentral.com.

Preparing tables

When preparing tables, please follow the formatting instructions below.

- Tables should be numbered and cited in the text in sequence using Arabic numerals (i.e. Table 1, Table 2 etc.).
- Tables less than one A4 or Letter page in length can be placed in the appropriate location within the manuscript.

- Tables larger than one A4 or Letter page in length can be placed at the end of the document text file. Please cite and indicate where the table should appear at the relevant location in the text file so that the table can be added in the correct place during production.
- Larger datasets, or tables too wide for A4 or Letter landscape page can be uploaded as additional files. Please see [below] for more information.
- Tabular data provided as additional files can be uploaded as an Excel spreadsheet (.xls) or comma separated values (.csv). Please use the standard file extensions.
- Table titles (max 15 words) should be included above the table, and legends (max 300 words) should be included underneath the table.
- Tables should not be embedded as figures or spreadsheet files, but should be formatted using 'Table object' function in your word processing program.
- Color and shading may not be used. Parts of the table can be highlighted using superscript, numbering, lettering, symbols or bold text, the meaning of which should be explained in a table legend.
- Commas should not be used to indicate numerical values.

If you have any questions or are experiencing a problem with tables, please contact the customer service team at info@biomedcentral.com.

Preparing additional files

As the length and quantity of data is not restricted for many article types, authors can provide datasets, tables, movies, or other information as additional files.

All Additional files will be published along with the accepted article. Do not include files such as patient consent forms, certificates of language editing, or revised versions of the main manuscript document with tracked changes. Such files, if requested, should be sent by email to the journal's editorial email address, quoting the manuscript reference number. Please do not send completed patient consent forms unless requested.

Results that would otherwise be indicated as "data not shown" should be included as additional files. Since many web links and URLs rapidly become broken, BioMed Central requires that supporting data are included as additional files, or deposited in a recognized repository. Please do not link to data on a personal/departmental website. Do not include any individual participant details. The maximum file size for additional files is 20 MB each, and files will be virus-scanned on submission. Each additional file should be cited in sequence within the main body of text.

If additional material is provided, please list the following information in a separate section of the manuscript text:

- File name (e.g. Additional file 1)
- File format including the correct file extension for example .pdf, .xls, .txt, .pptx (including name and a URL of an appropriate viewer if format is unusual)
- Title of data
- Description of data

Additional files should be named "Additional file 1" and so on and should be referenced explicitly by file name within the body of the article, e.g. 'An additional movie file shows this in more detail [see Additional file 1]'.

For further guidance on how to use Additional files or recommendations on how to present particular types of data or information, please see [How to use additional files](#).